DOCUMENT RESUME

ED 425 342 CE 077 721

AUTHOR	Hohn, Marcia Drew
TITLE	Empowerment Health Education in Adult Literacy: A Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders. Literacy Leaders Fellowship Program Reports, Volume III, Number 4, Part 1.
INSTITUTION	National Inst. for Literacy, Washington, DC.
PUB DATE	1997-00-00
NOTE	155p.; For other reports in this monographic series, see ED 400 426, ED 402 444, and CE 077 717-720.
AVAILABLE FROM	ED Pubs, P.O. Box 1398, Jessup, MD 20794-1398; Tel: 877-433-7827 (Toll Free); Web site:http://www.nifl.gov/hohn/HOHN.HTM
PUB TYPE	Collected Works - Serials (022) -- Reports - Research (143)
JOURNAL CIT	Literacy Leader Fellowship Program Reports; v3 n4A 1997
EDRS PRICE	MF01/PC07 Plus Postage.
DESCRIPTORS	Adult Basic Education; *Adult Literacy; Adult Programs; Basic Skills; *Empowerment; *Health Education; *Health Promotion; *Integrated Curriculum; *Literacy Education; Models; Participatory Research; Program Development; Program Implementation

ABSTRACT

This report explores one avenue for health education and promotion for audiences with low literacy levels: embedding empowerment health education directly in adult literacy programs. This approach emerged through participatory action research (PAR). The four sections correspond to the four questions around which the PAR process organizes the research. Intended audiences include public health and adult literacy practitioners, policy makers, and funders. Section I, "What is the problem?," provides multiple perspectives from public health, adult literacy education, and the target community. It cites literature supporting these concepts, summarizes research connecting literacy level and health status, and assesses social and political factors. Section II, "What are we going to do about the problem?," provides a description of how two major health education programs were carried out by a student action health team in adult literacy classrooms. Section III, "What did we learn from our action?," assesses what was learned in the programs, commonalities of findings, and how they merge to form a guiding model. The model is presented as a framework with fundamental components of empowerment health education in adult literacy. Section IV, "What do we need to share with others?," reviews research findings, implications for public health and adult literacy education policy, and recommendations for future funding. Finally, it includes suggestions for adult literacy teachers and public health educators for getting started. (Contains 140 references and instruments.) (YLB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 425 342

National Institute for Literacy

Literacy Leader Fellowship Program Reports

Volume III
Number 4, Part A

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Empowerment Health Education in Adult Literacy:
A Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders

CE077721

Marcia Drew Hohn, Ed.D.
Literacy Leader Fellow 1996-97

Empowerment Health Education in Adult Literacy:

A Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders

by Marcia Drew Hohn, Ed. D.

1996-1997 NIFL Literacy Leader Fellow

and

Director of Northeast SABES

System for Adult Basic Education Support
at Northern Essex Community College
45 Franklin Street
Lawrence, MA 01840
978-688-6089
mdrewhohn@aol.com

With many thanks to the National Institute for Literacy for their fellowship support that allowed the creation of this report.

The views expressed are those of the author and not necessarily those of the National Institute for Literacy.

Empowerment Health Education in Adult Literacy: A Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders.

©Copyright 1998 by Marcia Drew Hohn. All rights reserved.

These activities and other information contained in this project may be produced for educational purposes only, provided that the words "Created by Marcia Drew Hohn, NIFL Literacy Leader Fellowship Project" appear on the documents so reproduced. No part of this document may be reproduced or utilized in any form for profit, without written permission of the author.

This report is Part A from a collaborative fellowship
on connecting health and literacy education awarded to Marcia Drew Hohn
and Beth Sauerhaft by The National Institute for Literacy. Part A is
Marcia Drew Hohn's report of her project in Massachusetts.
Beth Sauerhaft's project in Berkeley, California will be published as Part B
and a special introduction will be developed linking the philosophy,
processes and conclusions of the two reports.

Dedication

This report is dedicated to the members of the Student Action Health Team who worked with me for two years in a Participatory Action Research Study to investigate and create knowledge about health education for low literacy groups:

Judy Berry
Marie Deshommes
Nguyet Nguyen
Ana Reynoso
Elsa Reynoso

...and to adult literacy students everywhere who continue to inspire me with their commitment to learning, growing and transformation in the face of frequently daunting circumstances.

Many thanks to the staff of Operation Bootstrap in Lynn, Massachusetts, for their cooperation, support and encouragement in carrying out the research. Special thanks also go to Vanda Ivaneko, Magali Torres and Charlene Wigfall who joined the Student Action Health Team in year two of the research project.

Table of Contents

Introduction

Low Literacy and Poor Health 1
Organization of the Report 2

How to Use this Report 5

Definition of Key Terms 7

Section I: What is the problem?

The Big Picture 11
Connections between Literacy Level and Health Status 11
Diagram- The Problem: Literacy Level and Health Status 12
Current Health Education and Promotion Practice 13

Public Health Perceptions of the Problems 14
New Perspectives in Public Health and Adult Literacy 15

Literacy Education Perspectives 16

Personal Perspectives and Background for the Study 18
Long Time Concern about Low-Literacy and Health Status 18
Personal Beliefs and Approaches 19
How I Came to Work with a Student Action Health Team 20
The Setting for the Study 21
Philosophy and Culture of Operation Bootstrap 23
History of the Team 24
Diagram: The Student Action Health Team: Who are we? What do we do? 27

Perspectives of Adult Literacy Students 28
First Level of Problem Identification 28
Diagram: What is the problem? Perceptions by Adult Literacy Students 29
Additional Levels of Problem Identification 30
The Participatory Action Research Cycle 30
Specific Areas of Health Work 31

Section II: What are we going to do about the problem?

Getting Started with Participatory Action Research 35
Team Process 35
Selecting New Membership 37
Diagram: What do we need to do about the problem? 41

Choosing the Health Topic....42
Diagram: How did we carry out a program?....46

The Cancer Education Program: Early Detection of Breast, Cervical and Testicular Cancer....47
Learning about Early Detection of Breast and Cervical Cancer....47
Developing the Educational Program....49
Carrying Out the Educational Program....51
Evaluating the Program....54
Taking the Work to the Outside....58

The Family Violence Educational Program....60
Getting Started....60
A Three Part Program Evolves....62
    Part One: The Child Street Safety Program....62
    Part Two: Effects of Witnessing Violence in the Home....63
    Part Three: Man-to-Woman Violence....64
Recruiting and Mentoring New Members....66
Evaluating the Program....67
Taking Our Learning to the Outside....68

Section III: What did we learn from our action?

An Evolving Model....73
Diagram: The Model: Partnering for empowerment health education in adult literacy....74

Community Relationships and Processes that Create and Sustain Power Sharing....76
Creating Environments....76
Importance of Context....79
Recreating an Empowering Environment for Operation Bootstrap Students....80
The Team, the Work, and Funders....82
Learning within Community....84

Active Learning in the Physical, Psychological-Emotional, and Cognitive Realms....84
Learnings from the Cancer Education Program....85
Learnings from the Family Violence Education Program....89
Drama, Sensitive Issues, and Culture....90
Time Required....91

Voice, Changing Perceptions of Self and Self in Relationship to Others, and Action-- Insights from our Evaluation....92
Diagram: How information is diffused....96

Language and Literacy Learning Facilitates the Dialogue about Health & Health Catalyzes the Motivation for Language and Literacy Learning.........98

Where are we now and where are we going?
The Student Action Health Team-- A Summary................................101

Section IV: What do we need to share with others?

Diagram: What did we learn from our action research?...................................107
Conclusions...108
Empowerment..108
The Value of Empowerment Health Education Embedded in Adult Literacy.....109
The Value of Health as a Context for Language and Literacy Learning.............111
Contribution and Limitations...112

Implications for Policy and Funding...113

Directions for Future Research...114

Some Suggestions for Practitioners: Getting Started With Linking Health and Literacy Education...116
For Adult Literacy Educators..116
For Public Health Educators..116
For Both Adult Literacy and Health Practitioners..117

References...119

Appendix A - Evaluation Survey in Cancer Program.....................................129

Appendix B - Evaluation Survey Results in Cancer Program..................................133

Appendix C - Evaluation Interview Questions in Family Violence Program..........149

Appendix D - Evaluation Interview Questions for Teachers.....................................151

Introduction

Low Literacy and Poor Health

We are facing a serious social problem in this country that has critical implications for both public health and adult literacy education. Recent studies have established connections between literacy level and health status and have found extensive evidence that low literacy, poor health, and early death are inexorably linked. This looms as a crucial social problem because there are large numbers of people in the United States with limited literacy. In this low literacy group, there are a disproportionate number of people of color and whites of low socioeconomic status who have a documented higher risk of poor health than the overall population. In today's health care system, health education and promotion are key strategies for maintaining and improving health. However, health education and promotion are primarily carried out through print materials written at a tenth grade or higher reading level. Therefore, the group that needs health education and promotion the most is the group least likely to benefit from the current practice. The major problem, then, is to identify effective means of educating low literacy populations about health issues so that their health status is improved.

This report explores one avenue for health education and promotion with low literacy audiences -- embedding health education directly in adult literacy programs. Based in a philosophy of empowerment, a two year participatory action research project was conducted in partnership with a student action health team. Together we identified and investigated the problems around health education for low literacy groups, designed and took action to address these problems, collectively assessed what we learned in the process, and what we needed to share with others.

Through the participatory action research, a model emerged that links health and literacy learning together in a power-sharing environment, utilizing the naturally occurring social contexts of adult literacy classrooms. Literacy learning was found to facilitate the dialogue about health and health learning to motivate literacy development. Voice, perceptions of self, and action in relation to health showed significant change.

Organization of the Report

Action is central to the core of participatory action research (PAR). In PAR, knowledge is created from the inside "out" through a process which involves learning from investigation and applying that learning to collective problems through social action (Park, 1994). In this PAR project we set out to learn about embedding empowerment health education in adult literacy through the process of actually doing it. We emphasized participation, collaboration and power-sharing.

The participatory action research (PAR) process organizes the research around four questions:

1. What is the problem?
2. What are we going to do about the problem?
3. What did we learn from our action?
4. What learning do we need to share with others?

This report is organized around these four questions. The first chapter addresses the question "What is the problem?" and reviews the research about connections between literacy level and health status. It also summarizes perspectives from public health, adult literacy education, adult literacy student groups, as well as my personal perspectives. Chapter Two, "What are we going to do about the problem?", is an in-depth exploration of the two teaching and learning programs carried out by the student action health team. These programs were implemented in various classrooms at an adult literacy program, and were the student team's action response to the problem defined.

Chapter Three, "What did we learn from our action?", synthesizes our learning from the two-year research experience and presents a model to guide empowerment health education in adult literacy. Chapter Four, "What learning do we need to share with others?", defines our broader conclusions and recommendations for both policy and practice.

Marcia Drew Hohn
December 1997
- with heartfelt thanks to the members of the
Student Action Health Team and the
National Institute for Literacy

How to Use this Report

This report is set up for easy and ready access to information by the variety of audiences that will use the information -- public health and adult literacy practitioners, policy makers, and funders. Each section is designed to stand by itself although a more thorough understanding would be gained from reviewing the entire document.

Persons interested in the rationale for the work and the research and theory in which it is based will want to review the first section "What is the problem?". This section "adjusts the lens", providing multiple perspectives on the problem from public health, adult literacy education and the target community. These multiple perspectives necessitate the inclusion of empowerment, leadership development and community participation as fundamental starting points. This section cites the literature that supports these concepts, summarizes the research connecting literacy level and health status, and presents an assessment of social and political factors.

Health educators and adult literacy practitioners may be most interested in the process of carrying out empowerment health education in adult literacy. Section II, "What are we going to do about the problem?", honors the complexity of the work by providing a detailed description of how two major health education programs were carried out by a student action health team in adult literacy classrooms. One program was on early detection of breast, cervical and testicular cancer and one was on family violence.

Researchers, policy makers, and funders may be especially intrigued by what was learned from the two year research experience and will want to review Section III, "What did we learn from our action?". This section assesses what was learned in each of the two health education programs, the commonalities of findings from both programs and how they merge to form a guiding model. The model is not presented for direct replication but as a framework with fundamental components of empowerment health education in adult literacy. The model illustrates the areas that one needs to pay attention to in order to do this work effectively.

Section IV, "Conclusions", may be of special interest to policy makers and funders. This section reviews the major findings of the research, its implications for both public health and adult literacy education policy, and recommendations for future funding.

The very last section is designed for adult literacy teachers and public health educators. It includes suggestions for getting started and cites valuable resources for conducting health literacy education.

Definition of Key terms

1. **Literacy** (Definition from the National Adult Literacy Survey, 1993)

--using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential. Specifically, it refers to functional ability in three major areas: prose literacy (extracting information from editorials, news stories, poems and fiction); document literacy (understanding job applications, payroll forms, transportation, schedules, maps, tables, and graphs); quantitative literacy (using numbers to balance a checkbook, figure a tip, complete an order form from a catalog and carry out similar tasks).

2. **Adult literacy** (Definition from the National Institute for Literacy, 1997)

--the educational system that serves adults who score in the bottom two of the five levels of reading, writing, and math skills identified by the National Adult Literacy Survey (NALS), who do not speak English well, or who do not have a high school diploma. The educational programs of the system are known as Adult Basic Education (ABE), English for Speakers of Other Languages (ESOL), and General Educational Development (GED). Adults in these programs are considered to be low literate.

3. **Literacy learners** --adults who participate in adult literacy education programs such as ESOL (English for Speakers of Other Languages) or GED (General Education Diploma).

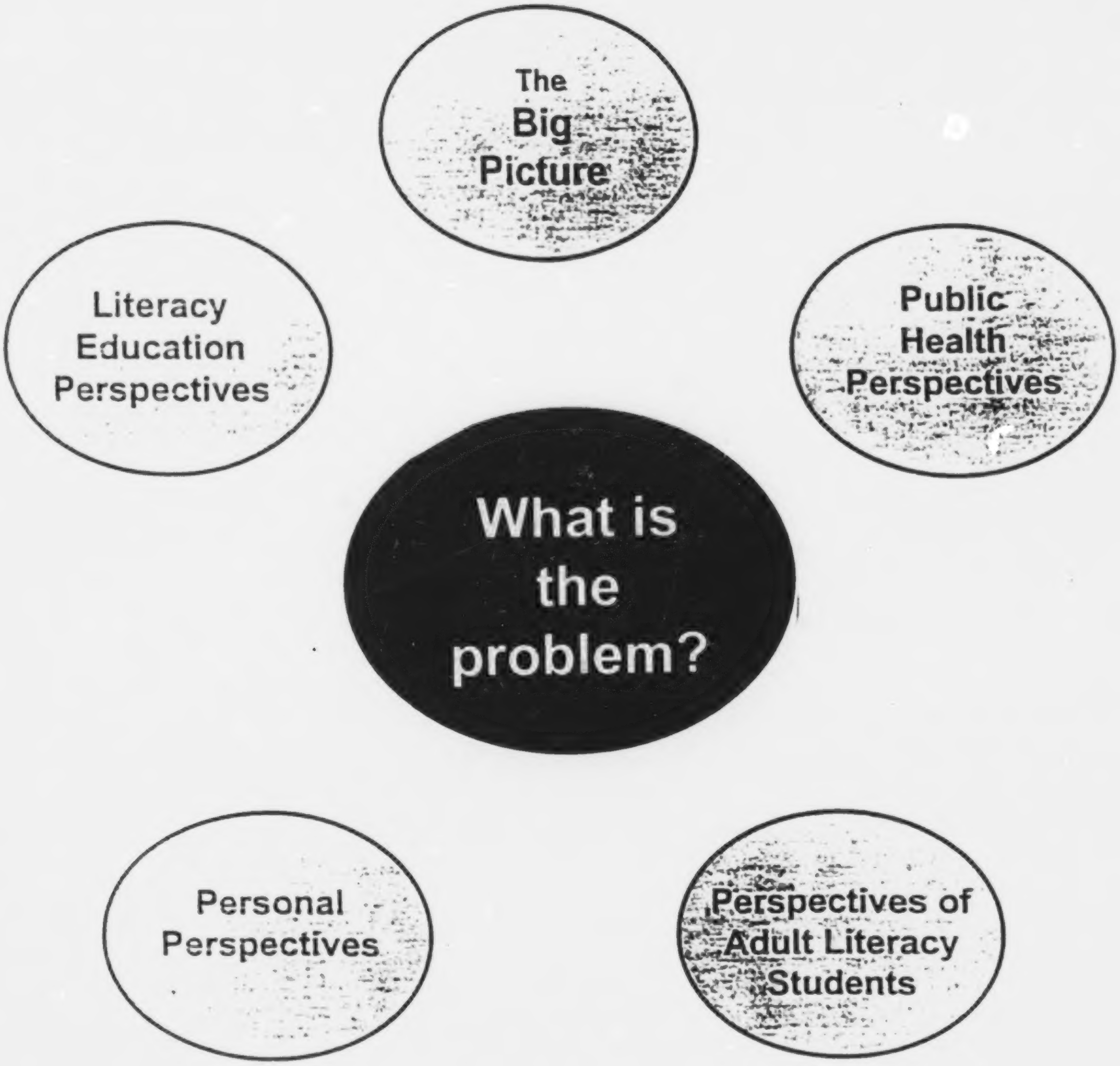
4. **Health education** (Definition from Health Behavior and Health Education,1988)

--a process to help individuals make informed decisions about matters affecting their personal health and that of others. Health education may range from patient education on managing a particular disease or medical condition in clinical settings to patient education to prevent or mitigate secondary complications, to public education among the general population, or among targeted groups, about prevention or early detection of disease and general well-being.

5. **Health promotion** (Definition from Healthy People 2000) --the range of activities that address the health needs of the general population or targeted groups and communities for prevention and early detection of disease and enhancement of health with an emphasis on developing a more holistic approach that targets basic underlying causes and requires multifactorial interventions.

6. **Empowerment health education** (Definition from Massachusetts Health Team Mission Statement and Airhihenbuma, Health Education Quarterly 21 (6), p. 346) --education about health issues that puts learners' interests, needs, and questions about health central to the process and where learners are active participants in the learning process. There is a focus on facilitating individual and community choices by supplementing knowledge acquisition with values clarification and decision-making practice through non-traditional teaching methods.

7. **Community** --a group of people who share common purposes and/or philosophy or goals.



What is the problem?

The Big Picture

Public Health Perspectives

Perspectives of Adult Literacy Students

Personal Perspectives

Literacy Education Perspectives

Section I

The Big Picture

Connections between Literacy Level and Health Status

Recent studies have established the connections between literacy level and health status and have found various evidence that low literacy, poor health, and early death are inexorably linked (Clenland & Van Ginniken, 1988; Grosse & Auffrey, 1989; Perrin, 1989; Weiss, Hart, McGee & D'Estelle, 1992; Tresserra, Canela, Alvarez & Salleras, 1992). Health status is the result of a complex array of many socioeconomic factors marked by income level, occupation, housing, and access to medical care (Healthy People 2000, 1990, p. 52). However, some researchers have identified educational level as the most explanatory of these markers (Pincus & Callahan, 1996, p. 7). Literacy level is a reflection of educational attainment, and is often a more accurate reflection of actual functional levels. Therefore, the discovery that 45 percent of the U.S. population (90 million people) has limited literacy skills (Kirsch, Junegeblut, Jenkins & Kolstad, 1993, p. 50) shocked and sobered the nation in general and health care practitioners in particular. These findings have resulted in a focus on specific health and literacy linkages, and have generated enormous concern across the spectrum of health care about how to work effectively with low literacy populations. In a health care world where chronic disease has become a major cause of sickness and death, and the locality of care has shifted to outpatient settings, health education and health promotion have an increasingly important function (Healthy People 2000, 1990, p. 82). Moreover, Health Maintenance Organizations (HMOs) have an economic interest in keeping their client groups healthy and they increasingly rely on health education as a prevention and early detection strategy (Sissel & Hohn, 1996, p. 63). Legal forces also play a role. Case law regarding the obtaining of informed consent from low literacy individuals, and requirements imposed by the Joint Commission for Accreditation of Health Care Organizations and the National Committee for Quality Assurance about the nature and form of information used in patient education, provide additional imperatives (Furnas, McCellan, Haywood, Ohene-Frempong & Taylor-Watson, 1996, pp. 38-39).

THE PROBLEM: *Literacy Level and Health Status*

Low Literacy Level and Poor Health are Directly Linked - The Research Base

Health People 2000 & Other Strategic Plans identify educational level as key determinant for access to health education promotion activities and health services.

Studies in non-industrialized nations indicate direct relationship between literacy level and key health indicators.

Studies in Canada by Perrin and in the U.S. by Davis, Weiss & Williams confirm interaction between literacy level and health, linking low reading level and poor health.

90 Million Adults in the U.S. Have Limited Literacy Skills- The National Adult Literacy Survey (NALS)

The NALS Study establishes that 45 % of the U.S. population (90 million) people have extremely limited (20%) or limited (25%) literacy skill concentrated in minority populations.

Health Education-Promotion Relies on Print Materials that Low Literacy Adults Cannot Understand

Health education-promotion is a key strategy in today's health care.

Most Health education-promotion material is in print form written at or above the 10th grade level.

Print materials frequently make cultural assumptions that are misleading or not understandable by different groups.

Therefore, the 90 million people who are in greatest need of health education-promotion do not benefit from current health education practice about prevention and early detection.

Graphic created by Marcia Drew Hohn, 1997 NIFL Literacy Leader Fellow, (978) 688-6089

Current Health Education and Promotion Practice

There is, however, a major paradox. Health education and health promotion activities are accomplished primarily through print material, written at the 10th+ grade levels by skilled readers for skilled readers (Chen, 1994; Doak & Doak, 1985; Ontario Public Health Association, 1992; Williams, Parker, Baker, Parikh, Pitkin, Coates & Nurss, 1995). These materials are of no use to the 90 million people with marginal literacy levels who are more likely to be African Americans, Hispanics, Native Americans or Whites of low socioeconomic status (Kirsch et al., 1993, pp. 32-33). The result is that there is a huge segment of the population, concentrated in minority groups, that it is effectively out of the loop for health education and health promotion activities. Yet this is the same population that has been found to have poorer health status overall with a higher incidence of chronic disease (Davis, Meldrum, Tippy, Weiss & Williams, 1996, p. 95), higher rates of infant mortality (U.S. Department of Health and Human Services, Public Health Service, 1991, p. 55), and who experience shorter life expectancy (U.S. Bureau of the Census, 1993).

Perrin and his associates (1989) found that persons with low literacy skills are less healthy due to a number of specific literacy and health linkages. According to their study, persons with low literacy a) cannot read medication labels and sometimes take medication incorrectly, b) fix formula wrong and may improperly feed infants, c) cannot read written instructions for follow-up care, d) are less likely to have had a PAP test or a blood pressure check, e) are less likely to have smoke detectors, fire extinguishers, or first aid kits in their homes, f) smoke more, g) drink more coffee, h) exercise less and i) get hurt on the job more frequently. Perrin also points out that because low literacy adults are also likely to be poor, they frequently live in substandard housing located in unsafe areas, and their jobs tend to be more hazardous.

The studies of Weiss et al. (1992) and Williams et al. (1995) affirm the interaction between literacy level (particularly reading level) and health status and outcome, and add new insights into the health and literacy connections. Their studies indicate that low literate adults may also be less healthy because they lack information about where to go and when to seek help, inhibiting their access to health care. Adults are expected to a) understand signage, b) locate health facilities, and c) comprehend written instructions, pamphlets and brochures about medical tests, management of medical conditions, treatment options and treatment protocols. The inability to read and understand them limits care.

Public Health Perceptions of the Problems

In the current public health debates, the problems are primarily seen as a) readability of health materials, b) measurement of patients' reading levels in clinical settings, c) how to do effective patient education in clinical settings, d) improving patient and doctor communications, and e) developing understanding of messages about prevention and early detection of disease (Chen, 1994; Williams et al., 1995). The focus in health education and promotion strategies remains on individual lifestyle strategies and behavioral changes which are dictated from the top down (Ruzek, 1996). Cultural or ethnic differences are presented as educational barriers to overcome--as deviance from white, middle-class norms of healthy behaviors, and the goal is to promote individual change to compliance with those norms (Zambrana & Ellis, 1995).

From this perspective, one could perceive the solution as simply a need to "beef up" literacy skills in the general population--a front-end loading approach to ensure that adults have the necessary reading, writing, and math skills to benefit from existing health education and promotion efforts. Another approach is to fixate on developing low literacy materials that would be readable for most adults. Still another approach is to develop new ways for health information to be communicated, ranging from simple strategies, such as drawings and tape recordings, to more complex techniques, such as inter-active video programs. While all of these approaches may play a role in addressing the dilemma of the health and literacy connection, others in both literacy and health care, believe that the problems are too complex to be addressed by any one approach. They believe re-assessment and re-thinking about how to proceed is required.

New Perspectives in Public Health and Adult Literacy

New perspectives are developing within both the public health and adult literacy worlds that question whether the problem is being framed in too narrow a manner. The problem is that there are large numbers of people in the United States with limited literacy. In this low literacy group there are a disproportionate number of people of color and whites of low socioeconomic status who have a documented higher risk of poor health than the overall population. In today's health care, health education and promotion are key strategies for maintaining and improving health. However, health education and promotion are primarily carried out through print materials written at the tenth grade and above reading level. Therefore, the group that needs health education and promotion the most is the group least likely to benefit from the current practice. The major problem, then, is to identify effective means of working with low literacy populations around health issues so that their health status is improved.

Magnani (1995, p. 2) reminds us that we must become "liberated from defining problems according to our own solutions" and to "break new ground by crossing disciplines." There is a need for health education and health promotion that people can understand and act upon regardless of their literacy level, culture or language. The experience of the literacy field has shown that inviting learners to be active participants in the learning process, and providing opportunities to work on identifying problems and constructing solutions, has moved learners from passivity to active engagement, enhancing the potential for positive change (Fingeret, 1990; Horsman, 1990).

Within public health, there are voices congruent with these perspectives, who argue for community empowerment as a primary goal for health education and promotion. Robertson and Minkler (1994) describe the paradigm shift occurring within health promotion, and some of the prominent features of this new thinking. In the new health promotion:

> 1 The definition of health and its determinants are broadened to include the social and economic context within which health is produced.

2. Emphasis goes beyond individual lifestyle and behavioral change to include the broader social and political strategies to achieve health.

3. Individual and collective empowerment are embraced.

4. Participation of the community in identifying health problems and strategies for addressing those problems are advocated.

A learning together approach, then, is of paramount importance. Learning together has the potential to honor the perspectives of local communities and different cultural perspectives, and to entail an exploration of the inherent diversity and structural equity issues. Learning together also has the potential to develop an informed community of adults who feel empowered to address issues of health and well-being in their own lives and to confront a health care system that ignores their informational needs.

Literacy Education Perspectives

While the practice of adult literacy education is varied nation-wide in both its depth and scope, there is an emerging body of knowledge about learner-centered, empowerment models of adult literacy, content-based instruction, and the integration of life topics into instruction. Adult literacy is placing greater emphasis on education in contexts immediately applicable to solving life problems. The thinking of two educational philosophers, Malcolm Knowles and Paulo Friere, has profoundly influenced the development of this emphasis.

Malcolm Knowles is known for his clear and coherent voice to the adult literacy community about the principles and practices of adult education. Knowles (1989) developed the andragoglical model which honors adults' "need to know" and utilizes immediate questions as a fundamental starting points. Knowles' model recognizes adults as responsible partners in the learning process and respects their current wealth of knowledge.

Paulo Freire is known for his vision of education for transformation and his articulation of the principles and practices of popular education. According to Freire, the objective of education is to change society through a process that is focused on achieving understanding as a means rather than an end. Education is people-centered and people-controlled and uses a dialogue approach in which everyone participates as equals and co-learners to create social knowledge. Critical thinking is developed through problem-posing techniques, designed to help participants recognize root causes of their place in the socio-economic, political, cultural and historic web of their everyday lives-- and then to propel them to action to take control of their lives.

Freire argued that traditional adult literacy approaches promote literacy as a set of monolithic skills existing independently of how or where they are used and as an individual deficit to be corrected, perpetuating the marginalization and disempowerment of learners (Auerbach, 1992). This leads to the "banking" model of education where learners are seen as empty vessels awaiting deposits of knowledge by the teacher who makes all the decisions and controls the process. According to Freire, the banking model "...supports the development of individuals who accept the passive role imposed on them and learn, along with a fragmented view of reality, to adapt to the world as it is and not to act upon it and change it" (Rudd & Comings, 1994).

In opposition to the banking model, Freire calls for "education for transformation" in which the goal is to enable learners to become active participants in shaping their own reality. Educators in the United States and around the world have struggled to refine, reformulate and expand the Frierean perspective. This struggle has given rise to participatory curriculum development (Auerbach, 1992), the problem-posing approach (Wallerstein, 1987), and the sprial model (Arnold et al., 1991).

In all these approaches, there is a basic belief that literacy is inexorably linked to social action. In this belief, "...literacy education is understood in the context of adults' lives, rather than separated from it. That context-- the community's issues, problems, aspirations, skills, cultures, languages-- creates the basis for literacy work as well as the tools to engage in it" (Fingeret, 1990).

Personal Perspectives and Background for the Study

Long Time Concern about Low Literacy and Health Status

I have been concerned about the low literacy and poor health connections for a long time. Through my work in adult literacy, I have become aware that low literacy groups have pervasive, often multiple, and very serious health problems that negatively affect their participation in educational programs. I also have become aware that low literacy groups are out of the loop for most public health education and promotion. For me, these issues constituted a critical social issue with social justice ramifications that needed to be addressed. As one of the regional directors in the Massachusetts State Literacy Resource Center, I have been in a position to take initiative in this critical arena.

In 1992, I joined a loose group of health educators and adult literacy practitioners who formed in Massachusetts to begin investigating how these issues could be addressed. This group later became known as The Massachusetts Health Team (MHT). Together, we promoted the participatory approach to work in health and literacy and developed a mission and belief statement that: a) defined health as inseparable from a myriad of interconnected social, economic, political and gender related factors; b) affirmed the potential for health education to influence health behavior and social change; and c) called for the participatory empowerment approach to health and literacy-linked education for low literate adults.

Through advocacy by the MHT, this philosophy was adopted by the Massachusetts Department of Education in their Comprehensive Health Education Projects (CHEP) which began in 1993. Funded through tobacco tax dollars, grants to adult literacy programs became available ($16,000 - $20,000 annually) to do health education through a participatory approach.

During this same time, I was undertaking doctoral studies in human and organizational systems. I knew I wanted to research health and literacy linked education but was uncertain where and how I would undertake this investigation.

Personal Beliefs and Approaches

My personal approach to research has been based in a deep belief in the ability of all people to learn, grow, and create. I have always admired those people whose lives have been mired in struggles and defeats, but who were able to pick themselves up and start again. I have great admiration for the courage of adult literacy learners. These are people who are likely to have been uncared for, without social support systems or economic resources, likely to be in poor health and at the margins of social systems. These are people who are likely to have fled native countries under great peril or immigrated to the United States in search of a better life, leaving behind all that is familiar and comfortable, and, sometimes, significant social status and economic resources. Yet, they are also people willing to take a risk to learn a new language, adapt to a new culture, or resume learning in the face of what is often a long procession of negative educational experiences.

I also have a deep belief in the power of participatory process, whether this process is in teaching and learning situations, in organizations, in institutions, or in larger society. I value processes that promote consensus, sharing, mutual respect and participatory decision-making and believe that our potential as individuals, as communities and as a society are enhanced by those processes. I believe in the need to create environments where the participatory process flourishes.

I did not, therefore, approach the study of connecting health and literacy education neutrally or passively. I brought a conviction that the work is critically important, with beliefs about people and processes, and with a need for action. These convictions, beliefs, and needs framed my choice to study health education embedded in adult literacy with participation and empowerment as fundamental starting points. Participation and empowerment are central to my core as a person, as an adult literacy professional, and as a researcher.

How I Came to Work with a Student Action Health Team

In 1994, I met members of the Student Action Health Team at Operation Bootstrap in Lynn, Massachusetts -- a CHEP funded team within my regional jurisdiction of the State Literacy Resource Center. I had interviewed them about their work several times and assisted them in preparing for participation in the annual adult literacy conference's showcasing of the health and literacy work. I had been impressed with these women--their thoughtfulness, their insight, and their commitment to working on health issues. Moreover, we seemed to have been able to communicate effectively, in spite of significant linguistic differences. At this point, I knew I wanted my research to be in the health and literacy area but I did not know how to focus the research and how and where to carry it out. Through my conversations with the team, an idea began to germinate. My research could systematically examine the experience of a specific, program embedded health promotion project using the participatory approach. I knew from my review of the literature that the recent research on the connections between low literacy and poor health, and the changing socio-legal landscape of health care, had generated significant interest and concern in health education and promotion with low literacy populations. I was concerned that the conversation was being framed only in public health terms. I had already been active in health and literacy initiatives that placed participation and empowerment as core concepts from which the work flowed. Further review of the literature supported and expanded the concepts of participation and empowerment. Participatory action research was emerging as the appropriate research methodology.

However, I needed a site and a group to participate with me to carry out the research. I first approached the director of Operation Bootstrap with the idea. She was enthusiastic about the concept of participatory action research and its congruity with Operation Bootstrap's philosophy and commitment to student empowerment. From the practical side, she saw that my presence increased the probability of sustaining the student action health team. When I met with the team about doing a participatory action research project together, I tried to be clear and honest with them that the study and work was to carry out research about empowerment health education. I told them I saw the research as being in support of them as a team. What they defined as needs, interests, appropriate actions, and assessment would drive the project, not my research agenda. We would learn together from our action, systematically and intentionally document processes, and enter into periodic reflection about our work. We would be equal partners and I could act as facilitator if they wished (although unpaid). They would continue to receive $10 per hour through the Comprehensive Health Project but since the small grant award would run out rapidly, we would need to seek additional funds when we made decisions about the nature of our work together.

I also emphasized that carrying out research with and through members of the target group for the research was an important idea that was gathering increasing support in the health and literacy education worlds. Therefore, it was very important that such research be written down and disseminated and I wanted them to be part of that process. I told them that I was committed to health and literacy work for the long term and if they were interested we would seek opportunities to continue the work together. If team members did not fully understand everything that I said, they did appear to perceive me as someone who respected them as individuals and as a team and were excited about the concepts of participatory action research.

The Setting for the Study

This study took place at Operation Bootstrap in Lynn, Massachusetts. Lynn is known as "immigrant city," hosting many waves of immigrant groups since the turn of the century. During the early part of the century, a thriving shoe making industry supported a vibrant economic and social community. The decline of the shoe industry led to Lynn's gradual but unstoppable slippage to become a low income and undereducated community with an increasing percentage of the population with limited English (Massachusetts Municipal Profiles, 1995; U.S. Census, 1990).

Located in the heart of downtown Lynn, Operation Bootstrap is the city's major adult literacy provider. Established in 1984, the learning center provides English for Speakers of Other Languages (ESOL), Adult Secondary Education (ASE, encompassing the more commonly known General Educational Development or GED programs), and general adult basic education (ABE). Operation Bootstrap is also home to a family literacy program in collaboration with the Lynn Public Schools called Evenstart, and a variety of specialized pre-vocational adult basic education programs. Two off site programs operate--one at the Lynn Housing Authority and a special workplace ESOL program at a local business. The Massachusetts Department of Education is the primary funding source.

Operation Bootstrap students are relatively young, primarily female, low income and from diverse ethnic and racial backgrounds. A recent demographic profile of the program shows the following distribution of characteristics: low income (87%), female (73%), male (27%), Hispanic (40%), White (32%), Black (20%), Asian (7%) and American Indian (1%). Seventy-five percent of the students are 25 to 35 years old and around half work full-time or part-time. Approximately 240 students are actively engaged in the program at any given time.

Like most adult literacy programs in Massachusetts Operation Bootstrap has neither luxurious physical space nor the resources to support a large, full-time staff. Eighty-five percent of the staff work part-time without medical benefits, including the director. Those unfamiliar with the realities of adult literacy programs might actually be shocked to walk down the narrow, dilapidated steps to the entrance and enter into the 4,200 square feet of limited space the program occupies. Six classrooms fan out around a T-shaped space, interspersed with small offices for the two counselors, and a very small administrative staff. Walls are a dingy cream color and the carpet is worn, torn, and stained. The director laughs as she recalls the dismay of visitors about the physical space.

> *They should have been at Operation Bootstrap six years ago when we rented space in the YMCA and classrooms were separated by cloth covered partitions that did little to screen noise or voices from the various classrooms. We think we have died and gone to heaven to have a space we can call our own and contained classrooms where you can shut the door. (interview, January 22, 1996)*

Philosophy and Culture of Operation Bootstrap

The first thing one notices about Operation Bootstrap is that no one shuts the door. There is a level of conversation, camaraderie, support, exchange of information, and learning together among the staff and students. The small coffee area behind the receptionist's desk is a favorite place to hang out and talk. Students, the director, the administrative assistant, the counselors, and teachers can be found sharing a cup of coffee or a soft drink, laughing and talking together. Everyone at Operation Bootstrap talks to each other. You also notice how pleasant and respectful the receptionist is as she fields innumerable phone calls and inquiries from current and prospective students. The director notes that:

> *...even though we have heard `I want to get my GED' or `I want to learn English' thousands of times, we have to remember that the phone call or the visit took a lot of courage for that individual and is the first step down people's long educational road. We need to treat every phone call, every visit with the respect it deserves. (personal conversation, January 22, 1996)*

The walls at Operation Bootstrap are covered with evidence of students' participation and leadership in the program. The entrance door has notices about the upcoming Student Council meeting, one wall is covered with a sheet of children's handprints from Family Night, and another wall has drawings and writings by students about their lives. One wall contains a community bulletin board where the Student Council has posted notices of community resources in and around Lynn, augmented by information brought by other students.

The deep commitment of Operation Bootstrap to the participation and empowerment of their students can be summed up in this paragraph about their basic philosophy, written for a recent funding request:

> *Operation Bootstrap is an instructional, learning and cultural center for adult students in the Greater Lynn area. The center provides a friendly, supportive environment, respectful of cultural and individual diversity. It is Operation Bootstrap's goal to enable students to assess their own strengths and needs, set appropriate goals, and develop meaningful strategies for learning. All students are encouraged to reach their potential and value their self-worth. The curriculum capitalizes on the uniqueness of the adult learner who brings a wealth of life experiences to*

> *the classroom. The participatory model provides a forum for sharing relevant and meaningful ideas. It leads the student to the realization that education is not an acquisition of information but rather the transfer of lifeskills to the process of learning. (funding proposal to the MA Health Research Institute, January 1996)*

As part of this basic philosophy and commitment to student empowerment, Operation Bootstrap had been organizing small student groups focused on special areas of interest. The students in the interest groups became peer educators, thus connecting students to each other, the organization, and the community at large.

One of these small group initiatives developed a student-led buddy system that paired new students with experienced students for the basic orientation to Operation Bootstrap. But most significant of these initiatives was development of a Student Council which the director has noted as "...the beginning of mechanisms to give the students some control over the program. If we hadn't had that experience, I don't think we would have thought of a student action health team" (interview, March 17, 1997).

As part of this basic philosophy and commitment to student empowerment, Operation Bootstrap had been organizing small student groups focused on special areas of interest.

History of the Team

The student action health team at Operation Bootstrap got underway in early 1994, funded through tobacco tax dollars administered by the Department of Education, and facilitated by an external literacy teacher skilled in participatory process. The initial members of the team were drawn from Operation Bootstrap classes, recruited through program-wide advertising and selected through an interview process by the facilitator.

The advertisement had heavily promoted the $10 per hour that student action health team members would receive for their work in the team, setting a new precedent for student work. Operation Bootstrap's director notes "...the $10 per hour was necessary for motivation and respect...it makes the statement that this is more than minimum wage work...this is something important you will do for the organization" (interview, March 17, 1997). One of the original team members also noted the importance of the money.

> *The $10 per hour was very important because I had never made this kind of money in this country. In the Dominican Republic, I was a government auditor and made good money but when I came to this country I had no English. I worked for a laundry at $3.25 per hour and then at the Women, Infants, and Children (WIC) program for $5.91, so this was almost double what I had been able to earn. I thought `wow, someone thinks my work is worth $10 per hour. It made me feel very good. (team member, reflection session notes, May 28, 1997)*

The journal writings of the facilitator indicate that the payments shifted the dynamics in the relationship between herself and the team:

> *Interesting and dynamic to pay students. I see how this changes the class dynamic, to pay the members of this group. When I'm the only one being paid, there is a sense that I have to be `earning' my pay--which is synonymous with `controlling' the situation or needing to be the `expert'. (journal notes, January, 1994)*

The initial team was composed of six women, all from different cultures and linguistic backgrounds. Cultures represented included Anglo, Chinese, Haitian, Hispanic, Russian, and Vietnamese. During the first two years, there was an emphasis on developing the team's awareness and knowledge of health issues, and the cultural and social aspects of health. The class was also a forum where members could give their opinions about what were the important health issues in the community and how they could be addressed:

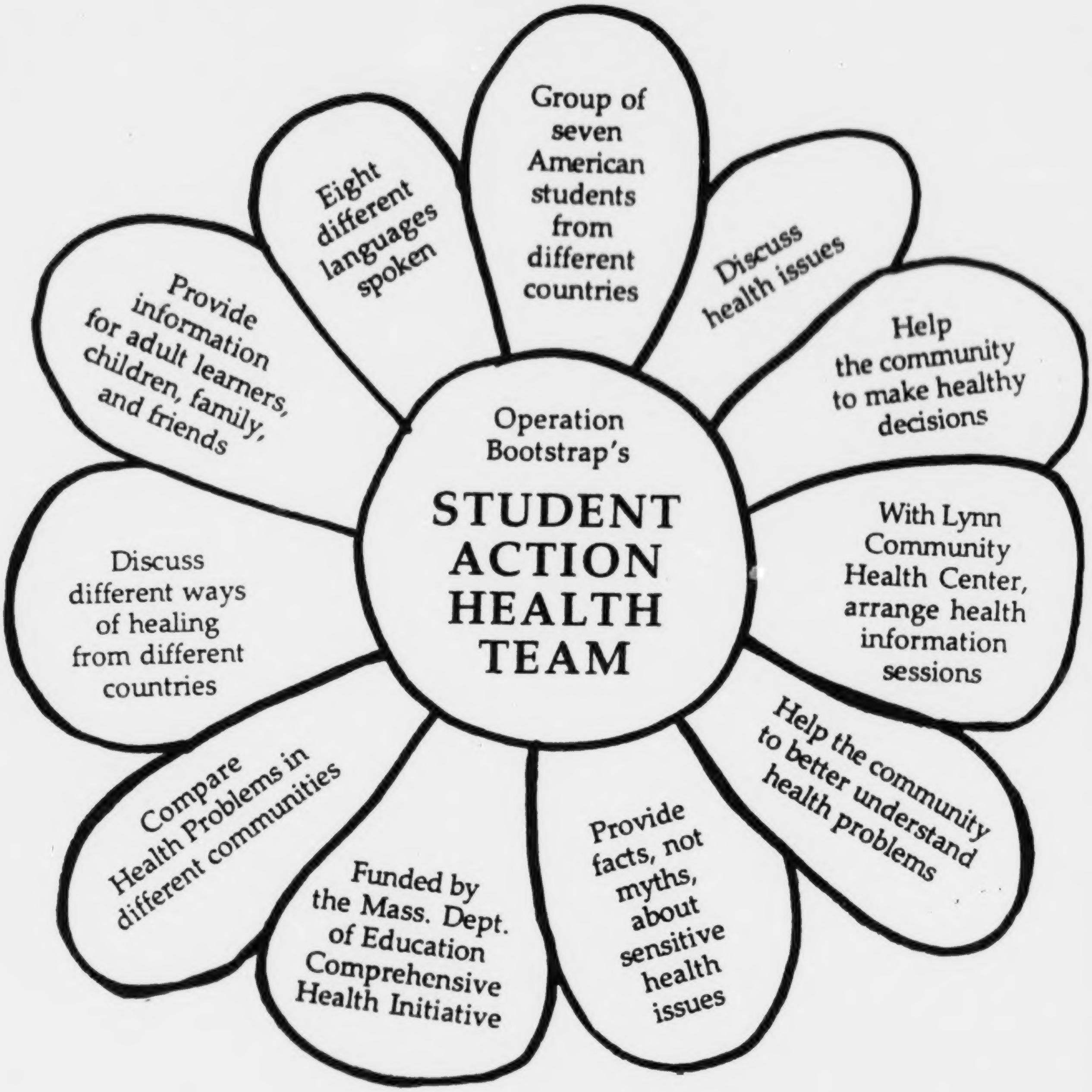
> *I saw my opinion was important and it felt good--in Hispanic families, the parents or the husband make all the decisions. I thought `oh my god, I have the right to speak and give opinions.'..We said that HIV/AIDS and drug and alcohol use were the biggest community health problems...and we found that the brochures to teach about these problems were too hard. No one understood words and everything was too crowded, too complicated...so we started with making simpler brochures...I made one on HIV/AIDS and on making healthy decisions. Everyone on the team, my family, and friends liked them and it made me so proud. (team member, reflection session, May 28, 1997)*

The team also undertook several surveys to determine health knowledge, attitudes, and beliefs about HIV/AIDS, domestic violence, and smoking among all Operation Bootstrap students. However, in the first year, the focus stayed primarily on the learning of the team and their development as a group. The participatory process and the opportunity it afforded to give opinions, coupled with the action of developing the brochures, made members feel strong:

> *The materials helped my personal growth. When we went to health fairs, many people came to our tables and saw our brochures and praised us, made us feel good, but when it came to teaching about health, we invited other people in to teach. We didn't have the confidence...that first year we were like a learning team. (team member, reflection session, May 28, 1997)*

One team member conceptualized the work of the team in a drawing of a flower that describes the range of resources within the team and the activities they had undertaken. Her drawing is figured on the following page.

What is the Student Action Health Team?
Who are we? What do we do?


Operation Bootstrap's
STUDENT ACTION HEALTH TEAM
Group of seven American students from different countries
Discuss health issues
Help the community to make healthy decisions
With Lynn Community Health Center, arrange health information sessions
Help the community to better understand health problems
Provide facts, not myths, about sensitive health issues
Funded by the Mass. Dept. of Education Comprehensive Health Initiative
Compare Health Problems in different communities
Discuss different ways of healing from different countries
Provide information for adult learners, children, family, and friends
Eight different languages spoken

Graphic Created by Ana Reynoso, Student Action Health Team Member

Perspectives of Adult Literacy Students

Health Education for Low Literacy Groups-- The Student Action Health Team's Perspectives

At the beginning of our work together, the student action health team had already decided some basic problems they wanted to address. The problems, they said, were that health materials were too difficult and that health education relied on the materials too much. There needed to be direct teaching and learning in Operation Bootstrap classes about health issues identified by the students as important, supported by good, low literacy print materials. However, the health educators the team had brought in to teach Operation Bootstrap students about health issues were ineffective:

> *We didn't have the confidence in ourselves to teach about health so we brought in outside teachers and had all the classes meet in the open hallway. The students told us it left them empty, that they didn't understand the words, what was being said. The teachers did not know the background of the students or their needs. (team notes, September 1995)*

The team, then, had already identified **three** major problems. First, print materials about health topics were too difficult. Second, even if the materials were written at appropriate literacy levels, they were insufficient by themselves in promoting active engagement with a health issue likely to result in behavior change. Finally, the team also discovered that many health educators were ill-prepared to do effective teaching with low literacy audiences. Therefore, the team had decided they needed to provide direct health teaching and learning programs for Operation Bootstrap students.

First Level of Problem Identification

This first level of problem identification led the Student Action Health Team to decide that they as a team needed to do the health teaching and learning themselves in cooperation with community health educators. They also decided that it was important to let the Operation Bootstrap students choose health topics. The team felt strongly that most health education and promotion was unconnected to people's everyday lives. By

What is the problem?

Perceptions by Adult Literacy Students

Print materials too difficult

Fear of Discrimination

No health insurance

Too Much Reliance on Materials

Health information not connected to everyday life

Health educators do not know audience

Lack of knowledge/experience with community health resources

No opportunity to ask questions

Psychologically-safe environment not available

Graphic created by Marcia Drew Hohn, 1997 NIFL Literacy Leader Fellow, (978)688-6089 giving students a choice in what to study, they saw increased potential for connection to real-life concerns and enhanced active engagement.

Additional Levels of Problem Identification

During the two years of the participatory action research (PAR) study, other problems were identified and addressed in the health education programs developed -- problems not often present in public health literature. One of the most important of these was the need to provide a psychologically safe atmosphere for health teaching and learning where people's questions would be respected and addressed. Inherent in this psychologically-safe environment was the need to respect different cultural perspectives, further connecting to everyday life through a respect for different belief systems.

Access to health care, especially for prevention and early detection was identified as another problem area. However, access was seen as a multi-dimensional issue. Embedded in access are issues of fear of discrimination and a lack of knowledge and experience with community health resources. It is not simply a matter of providing more community resources or advertising these resources. It is also about helping low literacy groups understand their rights and responsibilities in the health care system processes, and how to negotiate within this system.

The Participatory Action Research Cycle

These issues did not unfold in a neat linear manner. Participatory action research involves a cycle of problem identification, action, reflection, and learning from action and new actions. It is a highly interactive process during which assumptions are uncovered, insights develop and conclusions are examined and re-examined in the light of continuous learning from action.

What follows in the next section is the story of our PAR process that examines in-depth the experience of embedding health education and promotion directly in an adult learning center. Together, the student action health team and I worked to identify problem areas in health education with low literacy groups, took action to address those problems and carefully investigated our action in order to learn form it. Power-sharing and leadership development were fundamental to the entire experience.

We collected nine different types of data sources which we analyzed and re-analyzed throughout the two PAR years. We formed conclusions that we are confident will inform the development and practice of health and literacy linked education as well as informing policies that support and promote this new area of work. We share these conclusions in the third section of this report.

Specific Areas of Health Work

Specifically, we worked with two major health issues chosen by the Operation Bootstrap students as the health area they wished to address. These two areas were: 1) early detection of breast, cervical, and testicular cancers and 2) family violence. For these two areas, we developed three-part programs of five hours each, delivered in individual adult literacy classrooms (English for Speakers of Other Languages, General Educational Development, Adult Basic Education, Pre-vocational, and Family Literacy).

Here is our story.

What is the problem?

Getting Started with Participatory Action

Teaching and Learning about Health in Adult Literacy

What are we going to do about the problem?

The Cancer Education Program

The Family Violence Education Program

Section II

Getting Started with Participatory Action Research

Team Process

Our first meetings were marked by both excitement and nervousness with each other. We had our own small room across the hall from the Operation Bootstrap classrooms and we agreed to meet on Wednesday nights from 5 to 8 P.M. We began with introductions and getting to know each other exercises. The student action health team was small at this point with only four members plus myself. Two members were from the Dominican Republic, one from Vietnam and one Anglo born and raised in the local area. These team members had known one another for nearly two years and had a much greater comfort level with one another, and as a group, than with me, so it was necessary to spend time talking about what role they wanted me to play in supporting their health work. They were very clear that initially they needed me to function as the facilitator--organizing meetings, setting agendas, and facilitating the process in meetings. We defined the job of the facilitator as someone who makes things easy, who smoothes the path.

We also discussed how we would function as a team and how we would make decisions. A brief set of ground rules revolving around respect, confidentially, and commitment were developed--ground rules that were revisited and revised many times during the next two years. We agreed that decisions would be made by consensus, if possible, or by majority rule, if consensus was not possible. I would be an equal member of the team with no more or no less power than anyone else. It was my job to facilitate a democratic process, at least initially, and everyone's job to honor our ground rules and decision-making agreements.

Team members were very comfortable with standard facilitation techniques such as brainstorming, pair interviewing, voting using colored dots, and, the use of flip charts and markers. In the beginning, I was careful to use facilitation tools that were familiar and comfortable, but as we progressed in our work, I introduced new and different tools appropriate to a particular set of issues. One of the enduring favorites of these new tools was the affinity diagram that we used many times to generate ideas about how to proceed with a particular problem or issue. The introduction of new tools not only facilitated the process, but broadened the array of facilitation techniques that they could use in other settings, something that made them feel "proud of being someone who can facilitate a group myself" (team member, group reflection notes, May 13, 1996).

We also talked about the participatory action research process of problem identification, education, action and reflection, and some instruments we would use for keeping a record of our research work together. My field notes, our mutual journal writing, and records of periodic reflection sessions would be the initial instruments, with others to be decided as we identified problems and took action.

We agreed that one of the first steps was to enlarge the team, although funds would only permit bringing on one new team member until additional funds were secured. Last year they had recruited and then interviewed twenty potential new team members from the Operation Bootstrap student body and selected four of the applicants. Only one of the new team members had remained an active member of the team, but they had not heard from her in some time. Last year's interviewing and selection process had been enormously time consuming and exhausting. However, when Operation Bootstrap teachers suggested that they chose a "promising student" for the team to save time this year, the suggestion was firmly rejected. This was their team, they said, and what qualities they wanted for the new member and who was selected was their responsibility. They would be happy to have teacher input about dependability and willingness to work but the final decision lay with them. This was the first visible indicator of the power-sharing parameters that developed between the Operation Bootstrap staff and the team as we engaged in our work together.

The first agenda items, then, were to decide the qualities we wanted the new team member to have and how we were going to advertise the position. There was an additional need to decide how we were going to introduce the new member to the current Operation Bootstrap student body and find out what health areas the students were interested in having the team address with them. Two members of the team were still active at Operation Bootstrap One was now the family visitor for the Evenstart Family Literacy Program and one was taking evening ESOL classes in addition to classes at a local community college. However, the other two team members were both working and all in all, there was limited contact with the current Operation Bootstrap student body.

Selecting New Membership

The team had already decided they wanted to put on a health fair at Bootstrap for Bootstrap students. They saw that the health fair could also be used as a vehicle to recruit the one new member our funding could support. Several posters advertising the position were posted at the health fair and on the community bulletin boards at Operation Bootstrap. Ten applications were received and the team elected to interview five of the ten. The majority of applicants were women. The one man who applied was invited to an interview, but failed to come at the designated time and did not respond to follow-up telephone calls. Team members speculated that he was unwilling to be evaluated by a group of women--the reverse of many man-woman relationships. There was a general sense of relief that our new team member would be a woman with everyone feeling that this would make relationships easier to develop. Together we constructed the criteria for selecting the new members and a series of questions reflecting that criteria.

The criteria for selection of the new member included:

1. Representing a language and culture not currently on the team
2. Evidence that they had given thought to health issues among Operation Bootstrap students and in the wider community
3. Ability to articulate ideas about those health issues, and
4. Someone who appeared to be a team player and compatible with other members.

Strong English language skills was not one of the criteria. Most of the team members spoke very limited English themselves when they joined the team and said the health team experience had put their language learning far ahead and had given them the confidence and courage to speak English without being paralyzed about perfect language. "It is more important to be understood and to understand. When I stopped worrying about making mistakes or not saying things just right, my English and my confidence to speak improved a lot. We can help the new team member with the language" (field notes, October, 1995).

> *We were most taken with people's compelling personal stories about why they were applying for the team, stories frequently about severe health issues in their own lives.*

After each interview, we made a newsprint list of what we each thought was good about the candidate and anything that concerned us. It was interesting that the many things that emerged as "good" had little to do with how well the person interviewed. We were most taken with people's compelling personal stories about why they were applying for the team, stories frequently about severe health issues in their own lives. The interviews narrowed down the choice to two candidates, each having her own particular set of strengths. One candidate was currently in the Operation Bootstrap GED program and a recovering drug addict who told us " I lost my four children and a large chunk of my life to drugs and alcohol...I was a angry kid and nobody could tell me nothing and maybe I can help the students understand, to listen, to get information, to talk about health" (interview notes, December 6, 1995). She also told us about a blood disease she had since childhood called Porphyria, the seriousness of which we did not appreciate at the time. She was very open about her addiction and impressed the team with her openness, cheerful demeanor, and seemingly positive outlook. The other candidate was part of the Evenstart Family Literacy program at Operation Bootstrap and had also experienced drug and alcohol problems. Additionally, she was struggling with the care of a sister with AIDS. We were touched by her story about the hard shell of silence she had begun emerging from over the last few months. Members recalled how shy and afraid they were when they began in the team and how they would like to give the same opportunity for growth they had been given. It was interesting that the criteria for representing another culture and language not currently on the team became unimportant. Both of the two final candidates were White and born and raised in the Lynn, Massachusetts area. It was our feeling that these two women were both the type of people who would be an asset to the team. Both had clearly thought deeply about the health issues in their own lives and in the community at large, and already were actively engaged in community affairs. They appeared to be people who could integrate with the team easily and had the time available to do the work. The team was evenly split about the choice. The team now had six members, including me as the facilitator. A previously absent team member had returned to the team, in time for the health fair.

> *The process of making the decision was almost more important than the decision itself, warranting the time and effort processes took.*

We did the selection vote for the new team member different ways--by dots, by hand raising, and by secret ballot, discussing strengths and weaknesses of each candidate before and after each vote. A split remained. Each candidate got three votes. One team member suggested a technique for breaking ties from her country, Haiti. The name of each candidate was written down on four separate pieces of paper, each of which was then tightly twisted. All the twisted paper votes were put in a basket, shaken, and drawn randomly. The person to first emerge with four votes would be our new team member. Since we clearly could not get beyond the tie, everyone agreed this was a good idea and that they would be able to live with the random drawing decision. The GED student emerged as the choice and a team member called her immediately. It was more difficult to inform the other candidate. The team member who was on staff for the Family Literacy program agreed to talk to her at the program the next day. This team member would stress to her how difficult the decision was and how seriously we had taken her candidacy. A letter was written by the team to other applicants thanking them for their interest and time, indicating that if we secured sufficient additional funds we would be in touch with them.

At this stage of development in the team, and in the team's relationship to the Operation Bootstrap students, how decisions were being made was critically important. The process of making the decision was almost more important than the decision itself, warranting the time and effort processes took. It was critical that team members trust that I was going to honor my commitment to fairness and power-sharing in the team and that I would introduce and help us use processes that promoted democratic decision-making. The Operation Bootstrap students needed to trust that the health team was going to elicit and honor their health needs and interests, and that the team would handle selection of the new team members in a fair and thoughtful manner.

What do we need to do about the problem?

Adult Literacy Students Response

Teach about health in adult literacy classrooms

Address difficult issues directly

Talk culture

Use peer teaching whenever possible

Use varied teaching approaches such as drama, art, and storytelling

Let students choose the health topics to study

Use a participatory approach

Provide safe and respectful atmosphere

Graphic created by Marcia Drew Hohn, 1997 NIFL Literacy Leader Fellow, (978)688-6089

Choosing the Health Topic

At the end of the previous year there had been some discussion about the team putting on a health fair on site for Operation Bootstrap students. We decided that a health fair could serve multiple purposes. It could be a way of introducing the team, getting input about the health interests and needs of current Operation Bootstrap students, and advertising for the new team member.

The decision about the content of the health fair was an easier task than deciding about how to get input from Operation Bootstrap students about their health needs and interests.

The content of the health fair emerged through a combination of prior work of the team and community resources. In the last two years the team had produced a number of brochures and pamphlets on HIV/AIDS, simple in design and language because, they said, most of the brochures produced by health agencies were too complicated with difficult language and Operation Bootstrap students could not understand them. Moreover, some of brochures were offensive, ... "showing brown skinned people like they are the only ones who get AIDS" (field notes, October 25, 1995). They wanted to give out those brochures and have free condoms that could be obtained from the Massachusetts Department of Public Health.

They were also aware that there were several community programs promoting early detection of breast and cervical cancer through teaching breast self-examinations, and including free Pap tests and mammograms. A community health educator from the North Shore Cancer Center had approached Operation Bootstrap about doing a program about early detection and it was decided to have her be part of the health fair--a decision that led to an extensive and highly successful collaboration over the ensuing months. The local community health agency was also invited to do blood pressure screening and provide information about community services such as the Women, Infants, and Children (WIC) nutrition program.

The decision about the content of the health fair was an easier task than deciding about how to get input from Operation Bootstrap students about their health needs and interests. I had suggested that we post a list of possible health topics at the health fair and have a "community dot vote" so all the Operation Bootstrap students and staff could participate in selecting the health topics. Everyone thought this was a fine idea, but disagreement erupted over what was to be on the list of health topics. There was consensus on familiar topics such as HIV/AIDS, cancer (especially breast and cervical cancer), smoking, drug and alcohol abuse, and stress. Where disagreement arose, was around the issue of discrimination. Some team members clearly saw discrimination as a health issue creating stress and physical symptoms like headaches and upset stomach. More importantly, the constant stress of discrimination was seen as leading toward more serious health conditions and to poorer health overall. Other members of the team, myself included, demurred, feeling that discrimination as a health topic would be extremely difficult to address. After much discussion and several votes by dots, the final list that was presented to Operation Bootstrap students at the health fair included discrimination as a health topic in addition to thirteen other possible health or health related topics: HIV/AIDS, cancer (general), breast and cervical cancer, smoking, nutrition, violence and abuse, lead poisoning, drugs and alcohol, stress management, children at risk, parental stress, health insurance information (including Medicare/Medicaid), and where one can obtain health care in the community.

Where disagreement arose, was around the issue of discrimination.

The list of possible topics was placed on newsprint on the easel near the communal coffee area. Each Operation Bootstrap student and staff member was given three dots at the Health Fair to cast his or her vote for the three health topics for the team to cover during the year. The community nature and public display of the vote was a vitally important starting point for the team's health work at Operation Bootstrap.

> *The dot voting brought the Center to a different place. The students [and staff] saw that their vote counted and was going to be acted upon. It started everyone talking [about health issues] before the events. (interview with program counselor, March 11, 1997)*

The top choices were cancer (when combined with the vote for breast and cervical cancer) and discrimination. During subsequent discussions within the team, we made a decision to start with a general introduction to cancer and then focus on early detection of breast and cervical cancer. We knew that early detection increased chances of successful treatment for these cancers, and there were definitive steps that could be taught. We also knew that there were significant amounts of information and community resources available that we could draw upon, and, that free or reduced fee screening tests and follow-up care would be available to Operation Bootstrap students. Many Operation Bootstrap students, including team members themselves, did not have health insurance and were not part of community health programs where prevention and early detection was a regular part of their care.

> *Nevertheless, the Operation Bootstrap students were giving the team a clear message about the health issues that were important in their daily lives and where they perceived the need for information and discussion.*

Other health and health related topics in which Operation Bootstrap students expressed great interest (via their dot votes) were HIV/AIDS, smoking, nutrition, drugs and alcohol, and violence and abuse. Some interest was expressed in stress management, parental stress, and children at risk. Virtually no interest was expressed in insurance, community health care options, and lead poisoning. Undoubtedly, there was some confusion about terms on the list which we did not define or explain, and, undoubtedly both students and staff were limited by the scope of their knowledge about the health issues. Nevertheless, the Operation Bootstrap students were giving the team a clear message about the health issues that were important in their daily lives and where they perceived the need for information and discussion.

The team also had their opinions about what was important. Violence and abuse was one area they strongly felt needed to be addressed. Operation Bootstrap students had expressed interest and need in this area via their dot votes. Team members recounted their own histories and current situations, and team members knew from other students that it was a presence and reality in at least half of the Operation Bootstrap students' lives. The other "top" health topics (HIV/AIDS, smoking, nutrition) were all areas that the team had worked on previously and had developed materials and identified community resources. Violence and abuse, however, was an area with little information and resource. This was the area, then, that we decided needed special funding to investigate and develop a program. We initiated seeking grant funds to support this work, while simultaneously providing funds to sustain the team. Since we knew that getting funding would be at least a six-month process, we decided to start our search for these additional funds right away.

At this point, we were still under the assumption that we would be able to cover several health topics over the year. In retrospect, this was a naive assumption. As we developed and implemented the teaching and learning program about early detection of breast and cervical cancer and integrated discussions about discrimination into the program, it became clear that multiple sessions in individual classrooms were the more appropriate approach to effective teaching and learning about this health topic. It was only possible, therefore, to cover one health topic during the year.

How did we carry out a program?

Our 2-year Action Research Project

Evaluated and analyzed each program through surveys, interviews, and reflection

Let students choose the health topic by a "dot" vote

Addressed
- **Early Detection of Breast & Cervical Cancer**
- **Family Violence**

Taught by students for students

Developed 3-part program
- **Basic Information**
- **Hands-on activities**
- **Resources**

Learned about the chosen health topics ourselves

Collaborated with local health agencies and educators

Carried out programs in individual classrooms

Graphic created by Marcia Drew Hohn, 1997 NIFL Literacy Leader Fellow, (978)688-6089

The Cancer Education Program
Early Detection of Breast, Cervical and Testicular Cancer

Learning about Early Detection of Breast and Cervical Cancer

It was already early December before we were ready with our team, the first health topic of early detection of breast and cervical cancer (with an integration of discrimination issues) and a decision to seek funding for the next health topic of violence and abuse. We had already decided that we, as a team, needed to be the primary developers of the teaching and learning program. Prior experience with outside health educators had been poor. As a team member said,

> *They don't understand the students here, the language problems, and how to make the information connect to students' lives. They just come in, talk real fast and use a lot of words nobody can understand. (team meeting notes, December 1995)*

Our first task was to learn about the early detection of breast and cervical cancer ourselves. I knew about Project HEAL (Health Education in Adult Literacy) that concentrated on early detection of breast and cervical cancer and had been developing in Massachusetts during the past three years. HEAL was currently funded by the Centers and Disease Control to develop and disseminate a participatory curriculum model, and to train literacy teachers to use the curriculum model. In a lucky coincidence of timing, HEAL was offering training for literacy teachers in Boston during December. I called and asked if we as a team could participate in the training because we were intending to develop our own program at Operation Bootstrap. Project HEAL developers and trainers were excited about the prospect of literacy students becoming teachers about early detection of breast and cervical cancer and affirmed our participation in the program. So on December 12, 1995, four of us from the team set out for World Education in Boston, the site of an all day training to learn about material resources and approaches to teaching about early detection of breast and cervical cancer. We still did not know how we were going to integrate discrimination issues but we carried the need to do this in our heads, and hoped some ideas would emerge during our training time.

The HEAL training was aimed at introducing literacy practitioners to the materials in a resource kit that exhaustively covered all aspects of the early detection of breast and cervical cancer and provided an array of many different types of materials such as breast models, videos, articles, posters, and stories. Many of the materials were written at a low literacy level and were simple and direct. Of particular importance among these resources was a Sourcebook for teaching and learning about breast and cervical cancer which included an introduction about cancer in general and explanations, stories, and vocabulary lists about breast and cervical cancer in particular. The Sourcebook also provided a guide to participatory curriculum development. It was not intended as a prescriptive program but as an array of materials and processes to develop your own program.

> *A lot of the discrimination concerns relating to health, they said, seemed to revolve around the Operation Bootstrap students' fears about being poorly treated in a social sense at health care facilities and not knowing their rights and responsibilities in seeking medical care.*

The training was participatory in its approach and a welcoming environment. I had been concerned that the team members would feel intimidated by being in a group of fifteen literacy teachers but the tone of the session made them comfortable and all of us participated extensively in the conversation about methods and materials. At one point in the day, I excused myself to return some telephone calls. When I returned, I found team members working with one of participating teachers to develop a skit called "Going to the Doctor". The skit, they said excitedly, might start to get at some of the discrimination concerns of the students. Their thinking had been stimulated by some discussion over lunch. A lot of the discrimination concerns relating to health, they said, seemed to revolve around the Operation Bootstrap students' fears about being poorly treated in a social sense at health care facilities and not knowing their rights and responsibilities in seeking medical care. Most students did not have health insurance and were not likely to have participated in prevention and early detection programs because of this. Moreover, students were frequently limited in English and from cultures with very different approaches to health care. Students did not know what they should expect in terms of health care providers' attitudes, provision of interpreters, and how they related to uninsured people seeking services. They were afraid of negativity and hostile attitudes. The intent of the skit was to bring these issues out for discussion, share information about rights, and provide opportunity to think through coping strategies. The skit dramatized a very negative situation in which a limited English speaking woman without health insurance seeks treatment for severe abdominal pain and is rudely and inappropriately handled by a receptionist and nurse. The skit, as it ultimately developed into a drama, became a critical part of the teaching and learning about early detection of breast and cervical cancer. It opened the door to discussions about fear of discrimination in health care settings, set the stage for action about discrimination, and thereby helped to lower one of the significant barriers to accessing health care. The skit also opened the door for us to use drama as a way to get into difficult topics and issues. Drama became a mainstay in the teaching and learning of our health programs.

Developing the Educational Program

In subsequent team meetings, we explored the kit of resource materials, gathered pamphlets on breast and cervical cancer from local health agencies, reviewed videos on breast self-examinations, discussed our own experiences, and asked questions, consulting with the cancer educator who had assisted us at the health fair. Some important topics we wanted to teach were:

1. What is cancer?

2. Basic facts about breast and cervical cancer as they are known today (who is affected, why, and in what numbers).

3. Mammograms can detect lumps in your breasts before they can be felt.

4. You can do self examinations to find lumps in your breasts in between mammograms and clinical breast examinations.

5. Women have a greater possibility of surviving breast cancer if it is found early.

6. Pap tests can detect cervical cancer, which tends to be symptomless but is 100% curable if found early.

These are objectives that are congruent with those of public health. Where we diverged was the way these things were approached. We wanted the teaching and learning to be done in such ways that students would feel safe to tell their stories, ask questions, and even challenge information, so they would see the information as connected to their lives and the lives of their families and communities. A team member said in the car on the way back from the HEAL training that..."you can't just tell people something and expect them to change as a result. You have to find ways to start with where people's hearts are and to connect to things that mean something to them" (personal conversation, December 12, 1995). It was the Operation Bootstrap students' understanding of the information and their connection to the information that was important. We also wanted them to know about the controversies and issues that surround breast and cervical cancer. Overall, the team saw that the approach to be used must include: a) direct teaching by peers, b) a safe and respectful atmosphere to ask questions and talk culture, and c) creative and inclusive methods. Also, the teaching and learning approach needed to be supported by simple, easy-to-read materials.

> *"...you can't just tell people something and expect them to change as a result. You have to find ways to start with where people's hearts are and to connect to things that mean something to them."*

The teaching and learning program on early detection of breast and cervical cancer that evolved over the next four months had three sessions of about one and a half hours each--facts, self-examinations, and the drama "Going to the Doctor". Early on, we made the decision to do the program in individual classrooms (or combinations of smaller classes) during class time, sensing that the smaller groups of 20 to 30 students each, who already knew one another, would provide a more comfortable environment. We sought the teachers' cooperation in providing class time and asked them to go over a vocabulary list and to do some reading lessons on cancer in general (HEAL resources) prior to our coming in for the first session. We talked with the teachers about our general plan for teaching and learning to allay their anxiety about the topic as a classroom focus and their personal anxiety about breast and cervical cancer. Anxiety among the teachers was significant. One of the Family Literacy teachers expressed the feelings common to many of the teachers:

> *At first, I didn't want the team to come to do the breast and cervical cancer education. I was not comfortable...it wasn't just that it was embarrassing--it was that it was scary. But the way the team proposed coming in eased my tension. It was a personal approach about our needing to take care of ourselves...to have space and time to talk about this important subject." (interview, March 11, 1997)*

We decided to add testicular cancer because there were a lot of men in the classes. While we thought they would be interested in breast and cervical cancer because of their wives, sisters, mothers, or girlfriends, there would also need to be something specifically for them, especially during the session on self-examinations.

Carrying Out the Educational Program

When we came into the classrooms, the teachers introduced team members individually and then the team explained that the program was in response to Operation Bootstrap students' request for education on cancer and that we were going to concentrate on breast, cervical, and testicular cancer. We explained that we were focusing on these cancers because we were all at risk, either directly or indirectly, and because they affected the people we loved. We emphasized that these cancers could be detected early through a combination of medical screening tests and self-examinations and that finding the cancer early increased the probability of successful treatment. We told students we would be coming to the classes three times so there would be a lot of opportunity to ask questions, discuss the information, and find out about community resources.

We explained that we were focusing on these cancers because we were all at risk, either directly or indirectly, and because they affected the people we loved.

The first session was on basic education about breast, cervical, and testicular cancer. After posting the vocabulary on a large sheet of newsprint, including a definition of cancer, we used a true and false exercise. We wrote individual statements about these cancers on large strips of poster board. On the reverse side, we wrote down whether the statement was true or false, as known today. One strip read, "If you are not sexually active, you do not need a Pap test" (false). Another read, "One out of every eight women will develop breast cancer in her lifetime" (true). Yet another read, "Poor women die more frequently and in greater numbers from breast and cervical cancers than do women in other economic classes" (true). In the classrooms we held up each strip as team members took turns reading the statement out loud. In beginning level ESOL classrooms, we translated the statement into other languages present in the classroom and as the team's language capacity allowed (five languages). Each student was given two cards--yellow for false and pink for true. We asked them to vote whether they thought the statement was true or false. Then we flipped over the strip for the "answer". Right away, students started telling their stories around these statements and asking questions. While there was some embarrassment, often a lot of giggling and nervous laughter, and varying levels of comfort and discomfort along cultural lines, the students were obviously taking the information seriously. As an ESOL teacher observed: "There is a degree of attentiveness to the team that is much higher than with me...students respect each other ...[and] seeing people like themselves as teachers is important to students" (interview, February 24, 1997).

We also did agree/disagree exercises as a way to talk about feelings, attitudes, and beliefs. We posted three signs around the room: agree, disagree, and not sure. We read a statement about which students would be likely to have different opinions. For example, one statement read, "It isn't right to touch your breasts or testes." Another statement read, "Pelvic exams are always painful and embarrassing." We then asked people to go and stand under the sign that expressed their opinion and, when comfortable, to share why they agreed, disagreed, or were not sure. Not only did these exercises get people up and moving, but provided an opportunity for students to express beliefs, values, feelings, and attitudes about health in general and these cancers in particular.

The second session was on self-examinations. For this session, we called on a health educator from a local cancer center who had helped us with the health fair back in the fall. She brought many different types of breast and testes models with different sets of lumps that could be used to practice self-examinations. She did a general demonstration on both types of models and then we divided the class into small groups (by language in lower-level ESOL classrooms) and each of the team members worked with a small group to practice finding the lumps. We asked the health educator to work with the men since all of us felt shy about working on testicular self-examinations. The self-examination session was the most popular. Operation Bootstrap students appreciated developing a special skill and the opportunity to practice. As the program progressed and we realized the extent to which students were sharing information with their families, friends, and neighbors, we began supplying smaller models that the students could keep at home to show others how to do the self-examinations. It also became important to have models of healthy breasts to develop a sense of normal lumpiness.

Not only did these exercises get people up and moving, but provided an opportunity for students to express beliefs, values, feelings, and attitudes about health in general and these cancers in particular.

The last session was the drama "Going to the Doctor", in which a person with very limited English and no health insurance is callously treated in a health clinic. After the drama, there was a general discussion about what happened and what should have happened. We then had the class break into small groups by role (doctor, nurse, patient, receptionist) to figure out how to replay the roles. The drama was reenacted by the "actors" and "actresses" from each group. The reenactments illustrated much higher levels of receptiveness and helpfulness on the part of the health care providers and coping strategies for the patient. At this session, we also gave students information on where they, or their family members and friends, could go for free or reduced fee screening tests and follow-up care. In several cases, team members had visited the health care facility personally to see the procedure and how patients were treated. We also drew on experience of the students themselves at these health care facilities.

We carried out the three-part program in six different Operation Bootstrap classrooms over a period of four months, reaching over 150 students. I played a minor role in the direct teaching and learning, primarily in facilitating transitions and/or filling in if there were not enough team members available. As team members gained confidence in their ability to carry out the program they looked to my presence less and less.

Every session included lists of terms used and simple written materials about what was covered, or resources in the community. The word lists and written materials provided for vocabulary building and reading activities. Some teachers built on these materials creating crossword puzzles and matching exercises, as well as developing writing activities.

As team members gained confidence in their ability to carry out the program they looked to my presence less and less.

Of course, all did not go smoothly and we made many adjustments and changes as we went along. The various classrooms had different levels of receptiveness. The Family Literacy and ESOL classrooms, with a strong sense of classroom community and a broad approach to learning, were the most eager and active participants. The evening GED (General Educational Development) classrooms, with adults employed during the day and preparing for the GED test at night, were the least engaged. As a team we were not always consistent in our performance and interaction with the students. In some sessions only a few team members were available in that time slot and sometimes we were tired and distracted. In some classes, small groups of students dominated. However, there was evidence emerging that the program was going well and proving effective.

Evaluating the Program

Evidence of effectiveness was emerging through many avenues. The questions students asked indicated that they understood the information, and were engaged with it. Students were attentive during the sessions and stopped team members in corridors to eagerly ask when they were coming back for the next session. Team members who were also students or staff at Operation Bootstrap, observed that students continued to talk about the information and sought support from one another and from team members in going for medical tests. A focus group I conducted with teachers affirmed our observations and gave further evidence that students were understanding the information and taking action on it.

We were also evaluating the program on an ongoing basis at team meetings. However, since most of our energy was consumed with carrying out the program, our discussions were fragmented and incomplete. At the end of the four months, though, we engaged in an extensive reflection session. We drew pictures and shared with one another what we saw happening for ourselves as individuals and as a team and what we saw happening with and for the Operation Bootstrap students. While this session yielded important conclusions, we did not feel that we had the complete picture. In particular, we were lacking information about the effects on Operation Bootstrap students. We had anecdotal information, but nothing that gave a comprehensive picture of students' perspectives about the program.

> *...it became important to provide evidence of our impact that would be taken seriously by outside organizations.*

As our confidence grew significantly about the importance of what we were doing and about my clear priority to connect the work to the outside, it became important to provide evidence of our impact that would be taken seriously by outside organizations. Funders had made it very clear that the only assessment data they were interested in was behavioral change shown quantitatively. Given that, and our increasing political savvy, it was easy enough to decide that a survey instrument that would generate numbers would be the most appropriate tool to demonstrate impact. However, the content of that survey was not so clear. We did not want to define ourselves exclusively in public health terms. Since the approach to this evaluation was to be participatory, as was all aspects of the team's functioning, it was important that all team members have an equal voice in deciding what was to be covered.

To accomplish this, an affinity diagram was used. Each individual team member was provided with Post-its to write down the issues they thought were important for the team and the funders to know. Post-its were then grouped by the team by likeness or affinity. Three broad areas emerged:

1. What did participants perceive they had learned?
2. What did they think about teaching approaches used?
3. What actions had they taken as a result?

Using dot voting to set priorities, we each voted for six specific areas under each broad category. In pairs, we then worked to transform the top six specific areas into six questions that were appropriate at a language and cultural level. Limiting each category to six questions kept the survey short (total of 18 items). At my suggestion, it was decided to use a Likert-type scale for responses (1-5, strongly agree to strongly disagree).

The survey was distributed to all participating classrooms via the teacher in that classroom. We had waited too long to do the survey and many of the students who had participated in the program had already left. There was, however, a critical mass that remained. Teachers were asked to explain to students how to use the scale and to assist students with any language issues. Surveys were then returned to the team for compiling.

Results were compiled by hand. This was a laborious process, but an important one for everyone to have intimate knowledge of the responses. Each of us took six to eight surveys of the 42 returned. One person read the question and each of us read the number of responses in the one to five categories while one member recorded the number of responses on newsprint. When this process was completed, the numbers were totaled and percentages calculated. Many team members felt the percentages did not portray the information dramatically enough and that the numbers needed to be displayed graphically. Using computer software, the percentage numbers were translated to bar graphs (appendix B). Based on feedback from funders, we later inserted socio-economic and ethnic characteristics of the overall student population at Operation Bootstrap.

We were learning about surveys by doing a survey, and undertaking its analysis. This included our examination of the distribution and frequency of responses in each of the items on the Likert-type scale and discussion of the significance and meanings in the variations. For example, it was significant when all responses clustered in the agree side of the scale with no disagree responses or if responses were spread across the scale. Responses were also analyzed in terms of characteristics of the participating students and important factors in the overall environment. For example, one would expect a low percentage going for a mammogram since the average ages in participating classrooms ranged from late 20's to early 30's and mammograms are recommended at age 40 and older. Going for Pap tests for early detection of cervical cancer (and other gynecological conditions) was much more age appropriate and one would expect to see a greater percentage of action in this area. Given that many students did not have health insurance, the number of medical tests sought was a number that gained greater significance.

We also discussed and asked questions about the significance of the survey in terms of the bigger picture.

We also discussed and asked questions about the significance of the survey in terms of the bigger picture. Learning and behavioral changes were self-reported. How valid was this self-reporting? How long would a learning or behavior change be sustained? What role would the social, economic, and cultural realities play in sustaining change? If time had permitted, in-depth interviews could have been a valuable follow-up to the survey. Follow-up interviews could have helped us to gain deeper understanding of the responses, particularly in areas where the information was surprising or confusing. For example, many students indicated that the information was not new to them. It would have been valuable to explore with them how they perceived this learning experience as different and what did this difference mean to them. In undertaking the analysis, we developed an appreciation of both the strengths and the limitations of this survey and surveys in general. The survey was strong because it had the authenticity of being built from and out of the questions and concerns of the team who had designed and implemented the educational program. Being representative of the community of the students participants, and active participators and observers in the entire process, they were more in tune with what were appropriate and meaningful questions to ask. The student participants were also aware that the team had constructed this survey themselves, increasing the probability that the students took the survey seriously and thoughtfully. What was questionable about the survey emanated from sheer logistics around the construction and timing of the survey. The process of building the survey from the ground up took so much time that the actual graphic presentation was short changed. Lines were not drawn completely and presentation was too dense. Changing the nature of the Liekert-type scales (strongly agree to strongly disagree to very helpful to not very helpful) confused students. The survey could have been improved if we had piloted it in one or two classes (or in small groups of students) before wide-spread distribution. Time, however, has been of the essence.

In retrospect, it might have been more appropriate to have done some unstructured interviews with students first to uncover more subtle changes in thinking and knowing that could later be followed up by survey.

In retrospect, it might have been more appropriate to have done some unstructured interviews with students first to uncover more subtle changes in thinking and knowing that could later be followed up by survey. However, we were fighting time, a lack of experience with evaluation instruments within the team as a whole, and my increasing discomfort that I was dominating the process. We did come out with a professional-looking report that had been constructed, implemented, and analyzed through a collective process (appendix A). It became part of our learning and assisted us in taking our newly emerging knowledge about embedding health education in adult literacy to our funders and to the wider adult literacy and health communities.

Taking the Work to the Outside

While we were undertaking the breast, cervical, and testicular cancer education program, we were seeking funding for the work with violence and abuse we wanted to do next. We had been successful in obtaining several small grants that collectively sustained the team's current work. However, it was not until the Spring of 1996 that we obtained a modest grant to undertake the work with violence.

We were also seeking opportunities to present and write about our work, to gain recognition for the work, to connect to power structures in the wider health and literacy worlds, and to leverage additional funds. Project HEAL (Health Education in Adult Literacy) asked us if we would present at their spring institute. The institute was for literacy teachers and health educators from 16 states that were gathering in Boston for a two-day session about implementing the HEAL program on early detection of breast and cervical cancer education in literacy classrooms. Preparing for and carrying out this presentation in which we demonstrated how we accomplished our program was an illuminating experience for us. Not only did it force us to clearly articulate what we did, what approaches and techniques we used and why, and what we saw as effects and impact, but it reaffirmed to us how much we had accomplished. Our discussion with literacy teachers at the institute led us to observe that many of them seemed paralyzed by their own fear of undertaking such a sensitive issue in the classroom and by personal anxiety about their own health. They simply were not able to get started. Health educators were particularly impressed with the drama because, they told us, it opens the discussion about an extremely difficult issue that is a reality for limited English clients with no health insurance. The drama has, in fact, been videotaped and used in trainings for health educators in California and Texas (B. Sauerhaft, personal communication, April 16, 1997).

> *Not only did it force us to clearly articulate what we did, what approaches and techniques we used and why, and what we saw as effects and impact, but it reaffirmed to us how much we had accomplished.*

In the ensuing months we presented at two statewide conferences for literacy practitioners and one conference for students and teachers together. We also wrote an article for a publication by The New England Literacy Resource Center called "The Change Agent".

I had made it an explicit goal of the research to include all the team members in presenting and writing about our work together whenever possible. It seemed very clear to me that this was the point at which the participatory process often breaks down. This was not simply a matter of us as a team developing programs to translate public health information into understandable language in ways that could make meaningful connections to Operation Bootstrap students' lives. It was also about taking the knowledge of what we had learned in doing the program back to public health, to the wider literacy community, and ultimately to policy makers and funders.

Taking the breast, cervical, and testicular cancer education program to the outside made it difficult for us to move on to the next health topic. We had made a tremendous emotional and psychological investment. Preparing for conference presentations and writing articles had reinforced our attachment. Moreover, we had been naive to think we could cover two health topics during our first six months. We were already well into summer, and most Operation Bootstrap students were moving on with new groups of students being recruited for the fall. We did not know if the new group of students would want us to address violence and abuse, but decided to go ahead with our investigation and learning. If this was not the topic that the next group of Operation Bootstrap students wanted, we agreed we would carry out the violence work internally in the team, and address their health issue of their choice as a separate activity.

The Family Violence Educational Program

Getting Started

The proposal we had written called for us to review and evaluate four existing and identified curricula for teaching about domestic abuse in adult literacy programs and to organize what we felt were the best approaches and materials into a resource kit. We also said we would pilot selected activities in Operation Bootstrap classes and include this experience in the resource kit. The final stage would be developing a training for literacy students and teachers who wanted to use the materials.

Domestic abuse was a topic close to home. Several team members had experienced violence in their homes in the past and one team member was currently in a violent relationship. For all of us, violence against women was an emotionally wrenching topic. We spent many hours talking about how we could all help each other to remain psychologically and emotionally safe while doing this work. We set new ground rules, emphasizing confidentially, commitment, and support of one another.

The experience and knowledge within the team were great. However, we felt we needed to know what others, particularly women who had experienced abuse, said about the issue. We watched a number of videos of women talking about their experiences, read books and articles, and talked with Women's Resource Centers, the police, and the Attorney General's office. When we started getting the same information again and again, we stopped our investigation.

Then, using an affinity diagram where each team member contributed her individual ideas, we developed our objectives for teaching and learning about domestic violence. We wanted women to understand that:

1. You (the abused) are not alone and there is help.
2. Experiencing violence can affect you in your head, your heart, and your soul.
3. There are many types and kinds of domestic violence.

These objectives became our criteria for our critical review of the curricula. The process, however, felt heavy and unproductive. We still had no concept of how we would approach Operation Bootstrap students with the topic, even if they chose violence and abuse as their health concern.

Then, in late September, a momentous event happened in Lynn. A six-year-old boy, named Jesus De La Cruz, disappeared, the apparent victim of an abduction. Operation Bootstrap students, most of whom were parents, were terrified for their children. One team member wrote in her journal:

> *I had a very busy day today trying to help the Evenstart parents to understand the tragedy that happened two days ago. Everyone who came to see me, was upset, angry, and very unhappy....I thought maybe the Student Action Health Team can do some educational activities around child abuse in order to help Operation Bootstrap students as well as the Lynn community with this tragedy. (journal notes, October 2, 1996)*

Another team member also wrote about the missing child in her journal:

> *[It is]...hard to concentrate on what we're talking about due to the fact that all I can think about is that six year old little boy. He is on the news, he's in the paper, his picture is in the stores. I feel like I want to cry. I feel it in my heart. (journal notes, October 2, 1996)*

A Three Part Program Evolves

Part One: The Child Street Safety Program

It was at this point that we shifted our focus. While we knew we wanted to address man-to-woman violence at some point, we needed to start where everyone's head and heart was now. We had already planned another health fair at Operation Bootstrap to introduce ourselves to the current students, to select the health topic, and to advertise for new team members. At the health fair, the posted list of possible health topics for the year included violence prevention, health effects of discrimination, HIV/AIDS, eating right/relaxation and exercise, and how to stop smoking. Not surprisingly, the community dot vote was overwhelmingly for violence prevention. Given the extreme emotion around the abduction of Jesus, we decided to make the first part of the program on child street safety.

Not surprisingly, the community dot vote was overwhelmingly for violence prevention.

Drawing on both national and local street safety programs, we developed a special program for Operation Bootstrap students. It included helping parents develop complete records on each of their children, to be kept in their possession in the event of a missing child. Included in the records were fingerprints, videoprints (a short video showing the child in action), and a basic information card (height, weight, lock of hair etc.). This part of the program was carried out during family night at Operation Bootstrap, and at a special holiday party we gave for the children. The police came to do the fingerprinting and the team did the videoprints. We also visited each classroom to introduce the identification record and basic street safety rules and to do a series of dramas about stories strangers use to get children to come with them. The message around the dramas was to teach children to say no to strangers using such stories, to leave the situation immediately, and to go tell an adult they trust (No, Go, Tell). The idea was to give the Operation Bootstrap students some tools for teaching their children, and other children in their extended families and neighborhoods, about street safety.

In a later reflection session, a team member talked about what she saw happening:

> *Everyone wants to keep their children safe [and] street safety was a big issue in Lynn. Everyone was so worried, looking for, hungry for things they could do for their kids to keep them safe...this year we got involved with the whole community--doing things for the whole community...at the holiday party everyone was rushing to get the information for their kids, for their neighbors...my kid and his cousin went [to the holiday party] and then they went to tell their relatives about being fingerprinted and the videoprints. [We were] inside and outside Operation Bootstrap, responding to a real need. (reflection session notes, June 2, 1997)*

Part Two: Effects of Witnessing Violence in the Home

It was well into January of 1996 when we finished the first part of the violence program. It seemed appropriate to keep the theme of child safety, but we shifted the focus onto violence in the home environment. In the resource guide called "Helping to Stop the Cycle of Violence in Families" (Student Action Health Team, 1997), that we developed and wrote collectively as a result, we described the emerging program as follows:

> *[In the program on effects on children of witnessing violence in the home]...we used drama to show how a child, who we named Tommy, felt seeing violence over and over again in his home. Through the drama people could get into the situation in their head and hearts without feeling singled out.*
>
> *We did not want to "preach" to the students and tell people how to be parents. We wanted them to be able to talk about difficult situations in the home without bringing up bad memories.*
>
> *We talked about known feelings children have in their heads and hearts, and how children will react, such as getting depressed and having behavior problems. The two dramas we created were "Tommy at Eight Years", showing immediate effects, and "Tommy at Fourteen on the Streets", to show long-term behavioral effects.*

> *We wanted people to be involved and to talk about how to stop the cycle of violence in the family, the specific things that might happen to him, and what could help him. [After the dramas] we divided the class into small groups and asked the questions 1) what do you think will happen to Tommy? and 2) what can be done to help Tommy? We recorded the answers on newsprint. Afterward, we summarized all the ideas from all the classes and gave them back to the students. There were many wonderful insights and ideas. (pp. 18-19)*

It had been very difficult to find the information and research on which we based this program. Our usual process was to check five to six sources and, if they were all saying essentially the same thing, we considered the information sound. The effects of witnessing violence on children is an understudied phenomenon and it was only through the Internet search of one team member that we were able to locate organizations that could provide studies and information to us. This was not the case with man-to-woman violence. In this case, there was so much information that we were overwhelmed. It was only when we revisited our affinity diagram, through which we developed our objectives for teaching about man-to-woman violence, that we were able to develop the last session of our program.

Part Three: Man-to-Woman Violence

In the resource guide referenced on the last page, we described the man to woman violence session as follows:

> *To learn about man/woman violence we used a drama showing a man beating a woman and a neighbor calling the police. Carlos and Susan had been married for fifteen years. The police had been called five times previously...the police demand to see if the woman is hurt. She denies anything is wrong, but the police can see she is badly hurt. The man insists it is a private matter and demands the police leave. The police do arrest Carlos and the neighbor takes Susan to the hospital where she gets in touch with a counselor.*
>
> *We explored the many reasons why a woman stays in a violent situation. The follow-up drama is Susan talking to a counselor who is a formerly abused woman. This drama starts the conversation among students about what they can do if they know of violent situations. Most importantly, it showed how women get trapped and some things that will help break the cycle of violence in their lives. We were very careful to be responsible by saying things that did not blame women or tell them what to do. Students*

> *at Operation Bootstrap come from diverse backgrounds and many accept violence as normal in family life. We wanted people to know violence is violence and in this country it is against the law.*
>
> *...As with the "Tommy" drama, we used questions in small groups to encourage thoughtful conversation, asking the questions 1) Why did Susan stay so long? and 2) What would help Susan? We also researched local numbers of shelters, doctors, social services, and support groups, that we posted on a board. (pp. 23-24)*

In both parts II and III of the violence program, we were carrying out each session in individual classrooms, which provided a context likely to be comfortable for students. Teachers were understandably nervous about the topic of violence in families. We found ourselves experiencing the same nervousness. The words of one team member expressed our anxiety:

> *In the breast, cervical, and testicular cancer, we were doing something new in carrying out a program of teaching but it didn't have the challenge of something where people might fall apart...and in [last year's] work we had ... [the health educator] as our helper but a violence helper was not someone the team wanted. (special reflection notes, May 28, 1997)*

One teacher expressed the anxiety of the teachers in this way:

> *...with violence it is treading on dangerous ground. It will stir up a lot of anger from past experiences and issues of power in relationships, [and] different cultural issues...a lot of women in my class have been abused or neglected...maybe as many as fifty percent. (interview, March 11, 1997)*

In carrying out the program, then, we were careful to maintain a non-judgmental attitude, to use drama (and humor) as safety screens, to provide many opportunities for Operation Bootstrap students and staff to discuss the information and issues, and to emphasize resources for assistance within the program and in the local community. We were also careful to keep the teachers informed about exactly what we would do in each session and provide vocabulary, stories, and other reading that they could use prior to and after the sessions. A letter was written to students explaining that these sessions were part of the violence prevention teaching and learning they had requested at the health fair and were not directed at any particular individuals. We told them when we were coming to their class so they did not have to participate if the topic was too difficult for them--although no one elected not to participate. At this juncture, Operation Bootstrap students had a tremendous trust in the team's ability to provide information what would be useful and meaningful, and to carry out programs in ways that would be respectful of their needs, experience, and opinions. A letter written to the team from an English for Speakers of Other Languages Level II class (dated February 6, 1997) captures the strong, positive interaction between the team and the Operation Bootstrap students:

> Dear Health Team,
>
> We learned about keeping the children safe. We will teach them how to call 911. Don't take candy or money from strangers. Don't go with them. Don't help strangers. We will tell the children to remember No, Go, Tell.
>
> ...We learned about identification fingerprints, locks of hair, a picture, eye color, blood type, birthmark, height and weight, skin color, and videoprints, and what clothes the children wear. We liked the dramas.
>
> Thank you for your help.

Recruiting and Mentoring New Team Members

During the process of carrying out the family violence work, we also recruited and mentored new team members. Our funding allowed us to bring on three new members. The team wanted to extend the opportunities they had experienced to current students. Using the same process of advertising, team interviewing, and selection as in the prior year, three new members became the mentee members during the winter of 1997. While bringing in new members during the throes of intense violence work was difficult, we needed the energy of additional members. Colds and flu, work demands, personal crises, and life stresses were draining our time and energy. Carrying out the family violence work in the individual day and evening classrooms took many hours. The commitment and eagerness of the new members to learn gave a needed boost to our spirits.

Evaluating the Program

For this program, it was clear to us that the evaluation needed to be personal. Family violence was a topic of tremendous personal concern and experience, bound more tightly but less visibly in everyday lives and cultural perspectives. We elected to do one-to-one interviews, with team members interviewing the students individually from as many classrooms as possible. I was to do individual interviews with the teachers and the director.

In deciding the questions for the student interviews, a personal approach that was highly interactive and supportive in nature seemed appropriate. We used a group brainstorm to generate ideas about what to ask, then put those ideas into categories and discussed our ideas about each. A dot vote was used to prioritize the ideas in each category and then, working in small groups, we refined the priorities into six questions (appendix C). Some practice interviewing was undertaken.

In deciding the questions for the student interviews, a personal approach that was highly interactive and supportive in nature seemed appropriate.

We decided it was important to let students volunteer themselves for interviews. Team members would go to participating classrooms and explain the purpose of the interviews (our evaluation of our work) and ask who would be willing to be interviewed. In ESOL levels I and II, interviews would be held in the native language (the team now had a six language capacity) and translated by the interviewer into the team's common language of English.

Thirty-six one-to-one interviews were held with Operation Bootstrap students. Undoubtedly, in those interviews that were translated, some thoughts and perspectives did not come through clearly. Also undoubtedly, more practice would have provided greater probing and depth in the interviewing process. However, as with the survey used in evaluation of the breast, cervical, and testicular cancer education program, this was as much a learning experience about interviewing as it was an evaluation tool.

The student interview data, coupled with staff interview data (appendix D) and data from internal reflection sessions, provided a rich array of multiple perspectives about the family violence work. However, it was difficult to separate our learning from the cancer education program from our learning in carrying out the family violence work. Collectively, all our experience, hands-on learning, writing, presenting, and data from a variety of sources and people were adding up to a whole that was much greater than the individual programs we had carried out.

Taking Our Learning to the Outside

Collectively we wrote a resource guide about our violence work, called "Helping to Break the Cycle of Family Violence" which included a video of the dramas used in teaching and learning. The collective writing process entailed constructing sentences and paragraphs out of recall about the activities undertaken and why they were undertaken. The outside facilitator (who we hired) elicited the recollections through questions to the group and recorded them on newsprint for the group's collective review. Editing was undertaken after the body of writing emerged.

The collective writing process entailed constructing sentences and paragraphs out of recall about the activities undertaken and why they were undertaken.

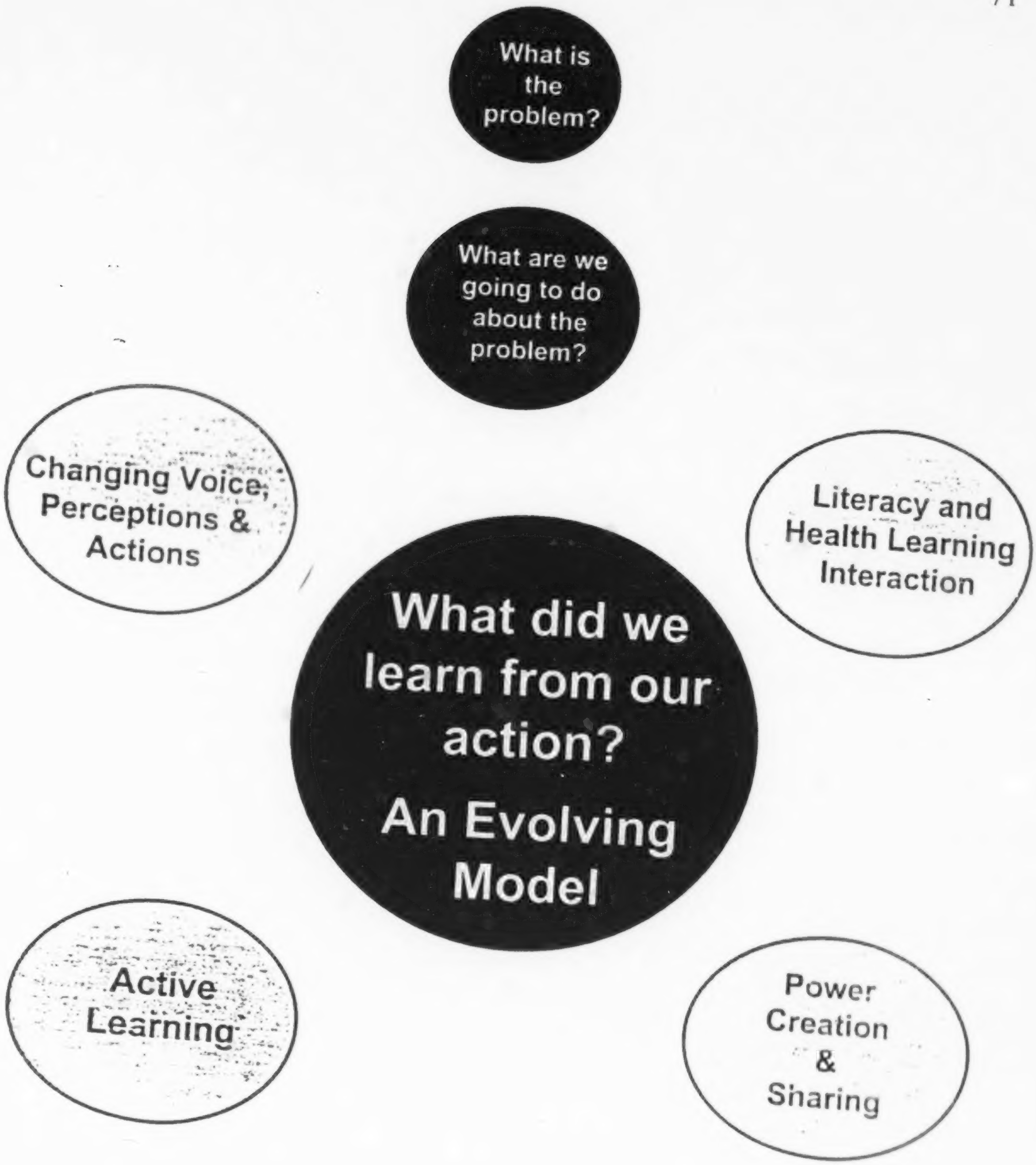
Additionally, we were presenting at conferences and special meetings. This time, however, it was to new audiences. One audience was a group of health care providers working in community settings. They were interested in the details of how we had done the education programs, but also wanted to discuss the applications of the work in other settings and for other health topics. We were already beginning to move toward articulating our work in terms of themes. The interests of our new audiences was moving us to think about models and frameworks.

At the same time we were moving toward themes, models, and frameworks, we made a major presentation in Washington D.C. to Congressional legislators and policy makers from the National Institute for Literacy. This opportunity had come through a fellowship I received from the National Institute for Literacy (NIFL) to develop a sourcebook on health and literacy work. I built funds into the budget to bring the team to Washington for a presentation. Through discussions with NIFL staff, the idea of presenting to legislators and policy makers emerged as a way to make the work of the fellowship more visible. During early 1997, a plan to present at the Russell Senate Building evolved, with an invitation by NIFL and the fellowship program.

The Washington presentation was the most difficult one for us to plan. The group was likely to have highly disparate levels of knowledge and need that was not knowable prior to presentation. We would be in an unfamiliar location and setting. We sat around one team member's kitchen table one Sunday afternoon, collectively wringing our hands about how to put this presentation together. While we did not expect great numbers and knew the attendees would be legislative and policy aides, this was the big time. Did we have the communal will and confidence to make this leap? One team member reminded us that drama has been our most productive vehicle for addressing difficult and sensitive issues. We also knew that modeling the approaches and methods we used in our teaching and learning programs at presentations had been an effective way to convey the nature of our work. Building off these two foundations, we designed a one hour presentation that included drama to illustrate how literacy level affects health. Through modeling methods we used in the classroom, we illustrated the depth of literacy problems in the United States and the need for literacy and health providers to work together. The Washington presentation was made on May 9, 1997 and was a defining moment in our history together. A team member described the experience in this way:

> *I saw that they were really anxious for the information--asking questions...the whole time their faces really listening and watching the drama. It was most important when the doctor came over to ask for more information. I said to myself, `he really wants this information'. They have never seen things done that way before. What I liked [most] was when we went over to the National Institute afterwards and Andy [the director] said, `you guys were incredible'. (reflection session, June 6, 1997)*

I am not naive enough to believe that receptiveness or praise means change. However, in our work together over the course of almost two years, and through the learning that has resulted, we have arrived at a new place in relation to the community that produces and monitors knowledge about health education and about literacy education. The door is opening for us to become part of that community now. We intend to walk through it.


What is the problem?
What are we going to do about the problem?
Changing Voice, Perceptions & Actions
Literacy and Health Learning Interaction
What did we learn from our action?
An Evolving Model
Active Learning
Power Creation & Sharing

Section III

An Evolving Model

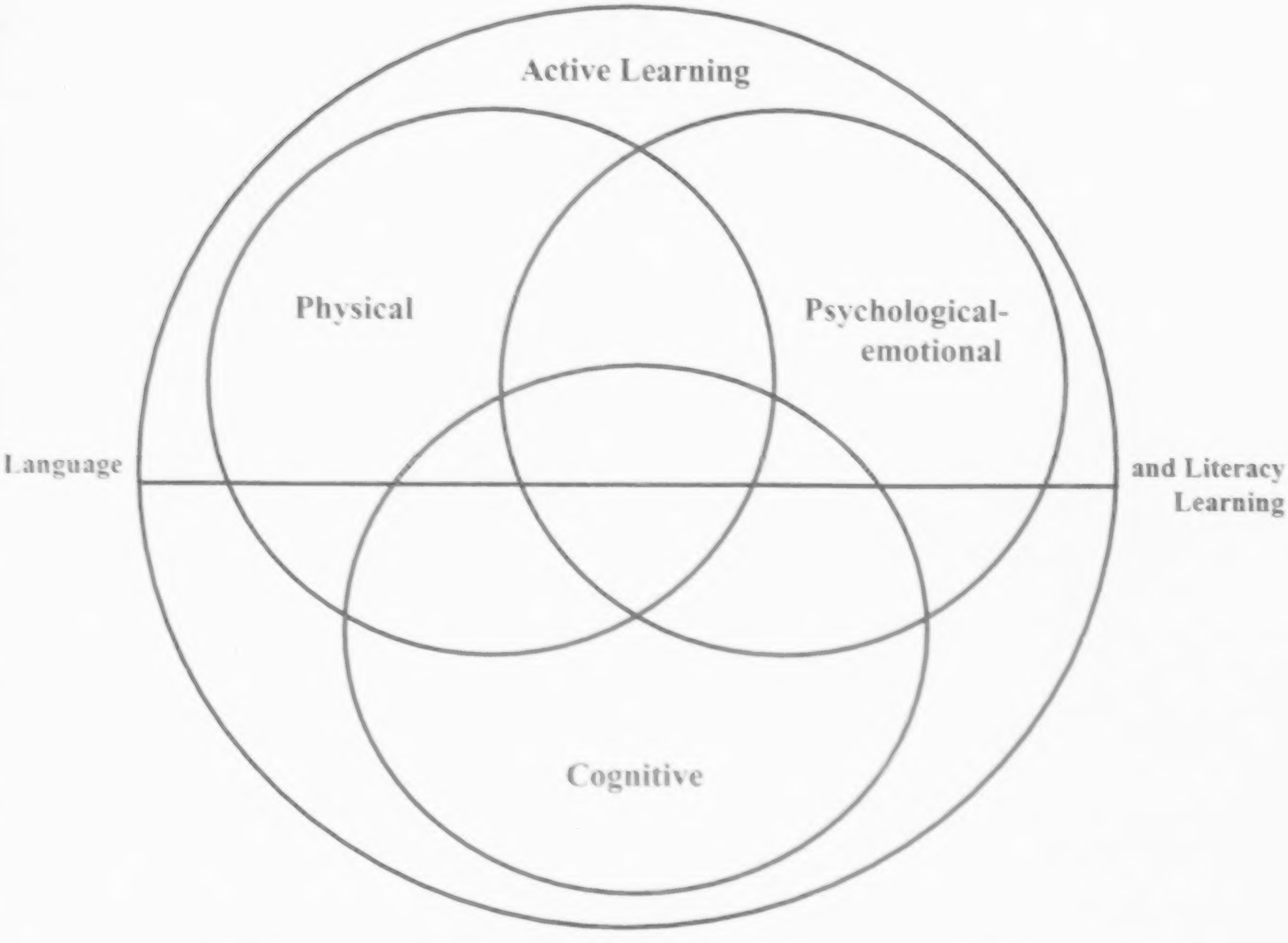
The model that emerged envisions empowerment health education as active learning in the physical, cognitive, and psychological-emotional realms. The learning realms form interlocking circles which comprise the center of a circle. The circle is encompassed by community relationships and processes that create and sustain shared power and by the concept of learning within a community. Intersecting across the middle of the circle are the language-literacy skills and behaviors that facilitate the dialogue about health. In turn, health as a topic and the centrality of the physical body as a context for learning provides tremendous energy, motivation, and commitment for literacy development. Literacy development furthers and enhances voice, changing perceptions of self and self in relation to others, and sets the stage for both individual and collective social actions.

In this model, health is not the starting point for language and literacy development. Health is introduced during the process of literacy development as a crucial life topic that motivates language and literacy development in adult literacy students. It is a two-way process. Language and literacy development facilitates the dialogue about health, while the topic of health simultaneously simulates the motivation for literacy learning. The components that form the model are seen as continuously interacting with one another. One does not cause another to happen. They are simultaneous relationships and processes that interact to enhance the others to grow and change in relationship to one another.

The model proposes partnering for empowerment health education that starts the teaching and learning embodied in people's individual and physical bodies--their body parts, their physical well-being, their physical safety--embedded in their perceptions of need for health learning. It is also language and literacy learning contextualized in people's bodies that goes beyond the physical body to the psychological-emotional body and the intellectual body.

The Model: Partnering for empowerment health education in adult literacy

Processes that Create and Sustain Power Sharing


Active Learning
Physical
Psychological-emotional
Language
and Literacy Learning
Cognitive

Voice **Learning within Community** **Action**

Changing Perceptions of Self

Created by Marcia Drew Hohn, NIFL Literacy Leader Fellowship Project, 1996-1997

The way in which the teaching and learning is approached moves the center of gravity away from the individual. This is relational learning and growing about health that utilizes the naturally occurring social webs of literacy classrooms, extending outward to families, neighborhoods, and cultural communities. It is based in multiple partnerships that create and sustain power-sharing, enhancing the sense of mutual responsibility and sense of agency about health, in both individual and community terms. Language and literacy learning, contextualized in the vital topic of health, moves literacy development beyond discrete skills to literacy behaviors that strengthen people's capacity to think critically about information and construct meaning about it, leading to a greater sense of power and control in their lives. It supports people in their many life roles and responsibilities and in the need to be validated as a whole person. Literacy development, then, becomes a tool for people to find their voice, to make their voice heard, and, ultimately, to make their imprint on the world.

> *This is relational learning and growing about health that utilizes the naturally occurring social webs of literacy classrooms, extending outward to families, neighborhoods, and cultural communities.*

One sub-theme threaded throughout the discussion is the concept of safety. It was surprising how often the issue of psychological-emotional safety of the social environment for learning about health emerged. The need to create the environment that prioritized psychological-emotional safety and maintained the time and space to sustain the safe environment was a vital part of the empowerment and learning process. The concept of safety also extended to physical safety--safety from disease, safety from environmental hazards, safety from the hostility of others, as well as the sense of physical safety that flows from a supportive and nurturing community.

The organizing concepts include:

- Community relationships and processes that create and sustain power-sharing,
- Active learning in the physical, psychological-emotional, and cognitive realms,

- Voice, changing perceptions of self, and social actions emanating from the interactions of the active learning in an empowering environment, supported through literacy development,
- Language and literacy learning as the facilitator of the dialogue about health and the catalyst for literacy development.

The following examines what was learned in two years of participatory action research about partnering for empowerment health education in adult literacy. Each of these organizing concepts used to create the model is discussed separately, and then as a whole as the concepts merge to form the model.

Community Relationships and Processes that Create and Sustain Power-Sharing

Creating Environments

From the beginning there was a clear sense that the participatory action research (PAR) must be conducted in an approach that reflects the theory, beliefs, and values from which it flows. A deep belief was held in the capacity of all persons to learn, create, and grow, and in the capacity of ordinary people to create knowledge. There was a commitment to build on their strengths and capacities and to build their leadership. Respect for multiple perspectives, participatory decision-making, enhancement of participants' self-esteem, and building of community solidarity and community spirit were strong values that guided the processes.

Participatory process is not a laissez-faire, hands-off approach.

In the initial stages, there is great responsibility on the researcher-facilitator in establishing an environment conducive to oneness and power-sharing. In setting the stage with the student action health team, it was critical that I employed participatory, democratic processes to establish an environment that made space for everyone's voice, balanced participation, and made decision-making processes clear and equitable.

Participatory process is not a *laissez-faire*, hands-off approach. It is actually the opposite, requiring significant time in planning, a sense of the appropriate tool at any given time, and the use of a wide variety of nontraditional approaches and methods for facilitation.

Valuing and mutual learning of the processes of collaboration and cooperation, consensus building, communal problem-solving, and participatory decision-making were critical pieces of our first steps together. Facilitation methods ranged from the traditional, such as ground rules and brainstorming, to the less commonly used story-telling, art, and generation of ideas through affinity diagrams. While some team members already had an orientation to participatory process in the first years of the team, there was not a high level of experience in democratic processes overall. Language issues compounded the difficulty. Five different languages were represented on the team, with English as the common language, and varying levels of proficiency and comfort with English prevailed. We had made the decision to use English in the team as members were anxious to improve their skill levels but the variety of proficiency and comfort made our communications labor-intensive.

In the course of our work together, several distinct elements emerged in the process of developing the team environment. These elements did not emerge in a linear manner. They developed interactively over the course of our work together, gathering strength as we moved forward.

The first element was choice. Choice included a) having access to health information, b) being respected for what you already know about health, c) listening to different cultural perspectives about health, d) having a right to probe and question the information, and, ultimately, e) having the time and processes in place to make informed choices about the relevant importance of specific health issues. Conflating all these components provided an open climate that emphasized options, choices, and decision-making.

In storytelling, we found a way to connect to one another's realities. It was also a way for us to connect a health issue to our own lives and to make sense of the health information we were reviewing. Stories were not just about health. They were about everyday life and there was often a considerable length of time devoted to general exchange that built a web of relationships in the team. Storytelling enhanced our capacity to listen to one another, to hear one another, and to be more sensitive and compassionate with one another, socially enabling each other's voices.

Through learning and experiencing together we became a community of knowers. When we learned or researched a health topic together, developed and implemented our teaching approach, planned our evaluation activities, developed and made a conference presentation, or wrote an article together, it bound us as a community of knowers with a common core of knowledge and experience. It created an aura of uniqueness about us as a distinct group of people who were moving forward together.

In storytelling, we found a way to connect to one another's realities.

Learning to trust and support one another was another vital part of our team development. As we built connections to one another around our health work, around language and literacy development, and in our personal lives beyond the team, we began learning how to trust and support one another. Whether it was assisting someone during a presentation, affirming one another's strengths, visiting in the hospital when one of the members became seriously ill, or attending funerals of members' loved ones, supporting one another in both our work and in times of personal stress was an important element in the creation of a psychologically safe and trusting environment that made our collective work possible.

One team member remarked that she was surprised that other women could help and support each other. "I never knew women could be my best advocates and good friends...I feel really good inside that I can talk to and talk with other women...we have become our own role models" (reflection session notes, May 13, 1996). In that same reflection session, other team members remarked on how proud they were of each other, how they saw the team as enhancing their individual and collective confidence. They also saw the multicultural nature of the team as a tremendous strength. Another team member, noted that "we are so proud of being a multicultural team...learning about different cultures...it has helped me in my job as a home visitor where I deal with people from different places...now when I go into a Vietnamese store [or home], I feel like I know something about it" (reflection session, May 28, 1997). The psychological-emotional environment of trust, safety, and support, the value and honor placed on participatory and democratic processes, the learning together approach, and our collective sense of partnership embodied the team. This embodiment of relationships and processes that created and sustained us flowed back and forth with the larger environment of Operation Bootstrap. As the work developed, the context of Operation Bootstrap as an environment emerged as critically important.

Importance of Context

One of the reasons I wanted to carry out the research at Operation Bootstrap is that I knew the staff was committed to being participatory and empowering at all levels. However, I did not appreciate how critical these commitments would be in supporting us in our health work.

The director of the program expresses the program philosophy this way:

> *Our goal is to be participatory at all levels...We wanted to develop mechanisms to give students some control over the program, to build their capacity and skill to become leaders focused in the context of work [for the program]. Leaders emerge out of the total picture and we need to provide a lot of avenues for that to happen. The Student Council was our first attempt. That experience led us to think about a student health team.... The more you do, the more role models you create, the more it ripples throughout the program. It is important to keep providing opportunities for both students and staff...it builds credibility...my heart's desire is to have more time to talk to students about what they want and what we could do together. (interview, March 17, 1997)*

Operation Bootstrap, then, was committed to the process of student leadership and to students as teachers. "I really like having students teaching students--peers are much more powerful teachers," remarked one teacher (interview, March 17, 1997). The staff saw health as a critically important topic. However, the way the topic was approached was equally important. They saw the need for the health concerns, interests, and questions of Operation Bootstrap students to be heard and ways sought to honor them.

They saw a student action health team as a vehicle for that to happen. They also saw the need to overcome the isolation surrounding health issues and to put health out into a social place for discussion. "Don't let your needs be defined by others or be cast in a deficit mode...your health is important. The health of everyone here [at Operation Bootstrap] is important...This is about us talking about health" (interview with teacher, February 24, 1997).

Operation Bootstrap staff also saw language and literacy learning as going beyond the classroom walls and the confines of traditional learning approaches. The staff's willingness to make time and space for our health team to carry out the programs in the context of individual classes, to participate in those programs as learners, and to facilitate the process through language and literacy activities were critical supports to our health teaching and learning programs. Their collaboration, cooperation, support, and willingness to share power nested comfortably with the emerging team environment to create and sustain the sharing of power. It was this congruity that provided the conditions for us to recreate a similar learning environment with the Operation Bootstrap students.

> *Operation Bootstrap staff also saw language and literacy learning as going beyond the classroom walls and the confines of traditional learning approaches.*

Recreating an Empowering Environment for Operation Bootstrap Students

The challenge for us was to find ways to recreate our experience with power-sharing around health with the Operation Bootstrap students, within the limits imposed by time and space of the Operation Bootstrap classrooms. We wanted to establish an atmosphere that told the students that the team was committed to making their health concerns and questions our starting point and the focus of our work. This commitment led us to the community vote to select the health topics for the year.

However, more was involved than simply choosing the topic. It was equally important that we design the educational activities in ways that would enhance students' understanding of the information, provide ways for them to relate the information to their lives and lives of others, and provide time to them to tell their stories in an environment that is psychologically safe and respectful of their knowledge, ideas, and questions. Team members also thought it was very important to provide basic information about a health topic as it is known today. This information was seen as a necessary base to enter in the discussion and the conversation about the health topic.

These goals were what led to the evolution of a four-part teaching and learning process for the breast, cervical, and testicular cancer education program and to reconfigure that process in the family violence work. The process was a simple four steps that could be applied to any health issue and consisted of a) providing basic information, b) hands-on activities for teaching skills and tools, c) drama to bring out difficult issues for discussion, and d) providing and discussing resources for the next steps or for obtaining further assistance. The ways in which the team carried out the program through simplified language, participatory activities, group discussions, translation when necessary, and use of pictures and graphics provided connections to students' heads, hearts, and spirits.

Team members also thought it was very important to provide basic information about a health topic as it is known today. This information was seen as a necessary base to enter in the discussion and the conversation about the health topic.

> *What I saw the student action health team convey to students was the strong message that their understanding was all important. Here is the information and here are the issues. If you need more information, we will help you find it.. The team doesn't try to pass themselves off as the experts. They are a tool to get to where the information is and the issues around it. (interview with teacher, February 24, 1997)*

The relationship between the team and the Operation Bootstrap students was one of reciprocal and mutual empowerment. For the team, the receptiveness of the Operation Bootstrap students to them as their teachers and their pride in being able to carry out a teaching and learning program of this magnitude with them dramatically changed their perceptions of themselves as individuals and as a group. In a collectively written article about the early detection of breast, cervical, and testicular cancer program, the team described their changing perceptions in this way:

> *At first, many of us on the team were very shy and afraid to talk in front of groups--because our English wasn't perfect or we were embarrassed because the information was about breasts and testicles...[but]the students were glad to have people like themselves as teachers. They told us they felt good about having a choice in what health area to study, and being able to ask questions and tell their stories. They told us they understood these cancers much better. We felt really proud we could carry out such a big program...that we could teach them so they could really understand the information. We see ourselves differently now--people who can work well with others, who are effective teachers, who are important to our communities, and who can make things change (The Change Agent, Issue 4, February 1997, p. 6).*

One teacher observed that:

> *Seeing their peers up there has been good for students' confidence. [Information] coming from friends, not authority, is different...having someone who spoke their language, understood their perspectives...there is something very important about learning from people like yourself...it opens up the topic of health for conversations and sharing of experience. [The students] always talked about [health] stuff afterward and referred to it in class on similar issues. (interview, March 17, 1997)*

Great congruity, then, existed among environments of the team, the Operation Bootstrap program, and the Operation Bootstrap classrooms. Here were environments in which the relationships and processes that create and sustain power-sharing were valued and acted upon. However, the congruity of power-sharing environments did not extend beyond the program walls. The sense of shared power began to fall apart when we bumped up against different perceptions of value and shifting priorities among funders.

The Team, the Work, and Funders

The student action health team was originally funded under tobacco tax dollars set aside for health education that were administered through the state Department of Education's Adult and Community Learning Services division. The stated intent of the programs at the time of the proposal request was to carry out participatory health education. However, there did not appear to be a widespread understanding of what participatory health education meant. The team had already experienced an eighty-eight percent reduction in funding the prior year due to shifting priorities within the Massachusetts Department of Education (MDOE). Funding new programs in lieu of existing programs had become a mandate within MDOE, even though the participatory approach had been discussed extensively as a three-to-five year process. Moreover, MDOE had expressed dismay that the health education programs across the state were not developing statewide dissemination plans, even though that objective had not been stated and was arbitrarily tossed into the mix of expectations for programs midway through the funding cycle. Empowerment from participatory process, therefore, seemed to be something that the state DOE felt they were bestowing upon the literacy programs and students--something under their power and control to withdraw at any time they chose. Participatory process was only viable as long as it did not conflict with any objectives determined at the top.

The reduction in funding had left us scrambling for additional funds. We found that the majority of health education funding comes attached to a disease or a body part with very specific expectations for both process and outcomes, and enormous control exerted in the name of accountability. What is valued are behavioral changes with the type of change determined from the top. Assessment of behavioral changes are only valued if shown quantitatively.

Funders have a responsibility to ensure that monies, particularly public monies, are used productively to promote a healthy population and healthy communities. However, the conversation about what is the definition of health, the social-political context of health, and what is possible, feasible, and desirable in health education is not a dialogue with the people doing the work or the recipients of the work. It tends to be a one-way process that devalues the voices of the community that is served.

This realization led us to seek small grants from the few organizations that are supportive of community participation and value the process and learning from the process as much as the results of the work. We also sought funding from specific sources where their goals were specifically in line with what we had already decided to undertake. While there was a sense of relief to be free from the controlling power of a large bureaucracy such as the state Department of Education, it was an exhausting and tensionprovoking process to cobble small grants together--especially for me as the prime grant writer. In our second year together, we came back to seek the more substantial state Department of Education funding, fueled by my need for a less exhausting funding process, but with deep mistrust and an adversarial power relationship.

Learning within Community

The context and the environments in which we carried out the teaching and learning about health were critically important. The atmosphere of environments, what is valued and honored, sets the tone for the work and creates or limits its possibilities. There was the great fortune to have congruity and compatibility among the team, the Operation Bootstrap program, and within the Operation Bootstrap classes in terms of philosophy and processes. The context for our work provided fertile ground and a supportive environment that allowed partnerships to flourish within the student action health team, between the team and the Operation Bootstrap staff, and between the team and the Operation Bootstrap students. It supported the creation of health teaching and learning that started with the needs and concerns of the community, took place within the community of classrooms, and maintained the focus of the community's stated needs and understanding throughout the process.

Active Learning in the Physical, Psychological-Emotional, and Cognitive Realms

The health teaching and learning programs that we developed over the course of the two years moved beyond the simplistic framework of just providing information with the expectation that people will act rationally on the basis of information given. Like everything in this research process, the programs emerged out of investigation of the health issue through both inside and outside resources and our own knowledge, dialogue, and discussion about that investigation, and trying things out in the classroom. It did not happen in an orderly, linear fashion and took many months to evolve.

Language and literacy learning was connected to the health teaching and learning through the written information provided to students and our collaborative work with the teachers. We provided vocabulary lists of words we would use and simple reading materials on the general topic to go over in classes prior to the first session. As we moved through the programs, we provided stories written by other literacy students about their experiences with this health issue, developed written handouts to reinforce verbal information given in classes, and recorded and summarized students' discussion about the health issue (if those discussions were part of the program). Students were reading this information and some teachers used the materials for writing exercises or located their own materials. They encouraged their students to write about their own experiences. Occasionally, games and other activities were developed. If there had been more time we could have worked more directly with teachers to connect language and literacy activities explicitly.

It is important to note that the health education came first. This was not a case where language and literacy learning was designed and health content applied to that design. The design of health learning was the primary goal, with language and literacy learning emerging both organically through the process, and sometimes explicitly connected to it. One of the most important findings of the research is that the tremendous energy and motivation to learn revolving around health issues catalyzes language and literacy learning and development in ways far beyond more traditional content areas such as citizenship.

Learnings from the Cancer Education Program--
Early Detection of Breast, Cervical, and Testicular Cancer

Our greatest learning was that you could not separate the dimensions of physical, psychological-emotional, and cognitive learning. They needed to be interactive. For example, teaching breast self-examinations or testicular self-examinations and providing opportunities to practice could not be divorced from opportunities for people to talk about their feelings and anxieties about touching their bodies. In some cultures and religious traditions, it is taught that touching your breasts or testes is wrong. At Operation

Bootstrap, we learned that among Southeast Asian cultures, Vietnamese in particular, there were strong traditions against even talking about reproductive systems, particularly reproductive systems of women. We used to tease the Vietnamese team member about the number of Vietnamese words she used to translate a simple sentence about breast or cervical cancer. This is because, she told us, there are not equivalent words in Vietnamese for terms such as cervix, and the concept of reproductive health simply does not exist. Just beginning the conversation with the Vietnamese women students about breast and cervical cancer took an enormous amount of preliminary discussion about concepts, terms, and feelings with the Vietnamese students.

The physical and psychological-emotional learning also cannot be divorced from cognitive learning.

The physical and psychological-emotional learning also cannot be divorced from cognitive learning. In teaching breast and testicular self-examinations, it was important to know why this was being shown: the reasons, the benefits, and the limitations. This was not just about teaching mechanics of self-examinations, but providing a safe and supportive atmosphere to discuss, not only *how* to do this but *why*, and what you think and feel, what your questions are, and perhaps your challenges. It was about placing Operation Bootstrap students as active participants in the process of learning about the facts as they are known today, the issues surrounding those facts, and considering what their relationship was to this information in the context of a supportive community. It was not about getting compliance, to get large numbers of Operation Bootstrap students to do self-examinations. It was about developing the students' knowledge, understanding, and skills around self-examinations and providing opportunity to connect the new health knowledge to personal experience so that they could engage with the learning. Storytelling, then, was a vitally important part of the process. It brought the information back into the psychological-emotional realm so that meaning and connection could emerge. What does this information and newly developed

Storytelling, then, was a vitally important part of the process. It brought the information back into the psychological-emotional realm so that meaning and connection could emerge.

skill mean for me? What does it mean for my wife, my husband, my mother, my aunt, or my sister? It was through telling their health stories that Operation Bootstrap students could connect their physical, psychological-emotional, and cognitive learning together to make meaning in their lives, for their lives, and the lives of their families.

The health educator who worked directly with us in the self-examination sessions, said that her time was best used when there was an environment in which she could do hands-on work coupled with discussion, and where there was safety to ask questions.

> *When I was in nursing school, the principles of community teaching were only minimally addressed. I have learned that [I need] to get with the population and their concerns and be flexible...[it is] not dumping materials....[My] time is best used when [we are] doing and discussing while doing. It is important that medical people go to them and there is safety to ask questions....[There are] legitimate concerns for everyone: 'Can I give cancer to another person?' 'Can I give it to my wife or partner?' (interview, March 12, 1997)*

The health educator brought models of breasts and testes. After a general demonstration, Operation Bootstrap students practiced with team members in small groups, organized by language in the beginning English classes. We most definitively turned the men over to the health educator for teaching self-examination of testes. She laughs about the ease with which she did this, recalling that she went into community health education because she was very shy and not comfortable with working with men (personal communication, February 12, 1996). As an attractive and young Hispanic woman, there was strong potential for her teaching to get mired in sexual overtones. In fact, within the team we had seriously discussed whether we should separate the men and women, but had made the decision to keep them together. There was strong sentiment in the team that the health of an individual, whether a man or a woman, was related to the health of families, neighborhoods, and communities, and that we needed to be learning together about health.

We were all learning about health together, the student action health team, the Operation Bootstrap staff, the Operation Bootstrap students, and the health educator. Every time we did a session, new information and new insight emerged from questions or discussion--not just about the mechanics of self-examinations, but about shared feelings, experiences, and stories. The opportunity was there to ask questions, such as the role of environment in the rise in breast cancer rates and why poor women die more frequently from breast cancer than do women from other economic groups.

Self-examinations was the second of three sessions we did on early detection of breast, cervical, and testicular cancer. It was the most popular of the three sessions and built off of the first session on basic information. It was followed by the third session that addressed fears and anxieties about discrimination when seeking medical care and provided substantive information about community resources to assist uninsured limited English people.

One teacher saw the session on self-examinations as the gateway and a springboard for the other parts of the program. As a participant in the health learning, she said:

> *We gained concrete knowledge. Most of us never had a chance to practice self-exams with a breast model. We were so reluctant at first, so embarrassed, but really got into it--learning to do breast self-exams right and hearing other women talk about it. [It is] important to being healthy, worthy of talking about, not dirty or shameful, or to be hidden. It increased discussion...and students made appointments for follow-up physical [clinical] exams...and were able to talk about it in class and get support. (interview, March 11, 1997)*

The physical nature of the work is striking. The photographs and videos show people examining breast models or testes models for lumps--a process they could replicate on themselves in private. Breasts, cervixes, testes, vaginas, and penises are shown and discussed openly. The physicalness is the core. This is learning about one's physical body and its safety. However, the learning rapidly fans out to the psychological-emotional:

> "What if I am too frightened to talk about breast cancer because my mother died from it?"
>
> "How can I examine my breasts if I have been taught that touching the sexually related parts of my body is wrong?"
>
> "What does breast or testicular self-examinations have to do with me, if I believe my health is more about my internal harmony?"
>
> "What if my language does not even include the terms for body parts?"

> "If I have no insurance or I have limited English, how will health care providers interact with me?"
>
> "If it is discovered I have cancer, will I be able to get medical treatment?"

The team saw that students need to be able to ask these questions and consider the information in light of basic facts.

Knowing and understanding the basic facts, as they are known today, is also crucial to the process. If my literacy level has prevented me from understanding written public health information, then I need the opportunity to learn about and understand the reasons behind the breast self-examination, PAP tests, mammograms. I need to know that breast cancer rates have increased to affect one out of every eight women in the United States, and while it is not known why, the environment is suspected of playing a significant role. I need to know that breast self-examinations, combined with clinical exams and mammography, help detect breast cancer early and increases my chances of survival. I need to know these are not perfect tools, but they appear to be the best there are so far.

Learnings from the Family Violence Education Program

In the family violence program, opportunity for the interaction of learning within the physical, psychological-emotional, and cognitive realms was also provided. In the session on street safety, children were fingerprinted and short videos (for identification) were taken showing them dancing, laughing, and talking. Drama was used to illustrate stories strangers use to get children to come with them. In the family violence dramas, beer cans are thrown, a child hides from a violent fight between his parents, a man beats a woman, a neighbor calls the police, and the police handcuff the man. Operation Bootstrap students worked in small groups to process the dramas and dialogue about what was happening, why, and what could help. Basic information was provided:

> "What are the statistics about runaway and abducted children?"
>
> "What is the research illuminating the short and long term effects of witnessing violence in the home on children?"

"What is the cycle of power and control in abusive relationships?"

"What resources can I draw on to assist me?"

One team member talked about the effects of interactive learning in this way:

> *People needed the information on violence [effects on children of witnessing violence in the home]. I did the translation with the Haitian students [in beginning English classes]. In Haiti, people don't think about what happens to children. [Now] there is a realization of its importance. They came to me with a lot of questions about their feelings. They grew up seeing those things [violence within the family], but didn't understand or know or were aware of what this does.*
>
> *With the drama, we didn't have to talk. [It was] doing it, seeing it...[it didn't] need words. It's like a baby...seeing those golden arches of McDonald's [restaurant]. [The baby] knows what those golden arches mean.*
>
> *Seeing violence as causing violence was a starting place, a beginning. It's like solving a puzzle...we gave them a piece of the puzzle, but it opens up the whole puzzle for them...opens everything up for discussion. Some people have the problem, [but] keep it inside. This opens up a space. I don't have to be afraid. I can talk about it, get help. [It is] shedding light into the dark. (reflection session notes, June 2, 1997)*

Drama, Sensitive Issues, and Culture

The use of drama was foundational to the way we approached difficult topics. Early on, we had made the decision not to fixate on different cultural beliefs, and to let those beliefs emerge organically through the process of discussion and dialogue. The diversity within the team gave us the cultural competence to be aware when something might be an issue or difficult for students from a particular cultural background. Drama was a way to approach a sensitive issue without putting anything out as truth or being judgmental. A team member talked about the use of drama in this way:

> *Drama breaks the ice between the student action health team and the [Operation Bootstrap] students. It is a nice way to approach a sensitive issue without getting into bad feelings or bad memories. It treats a sensitive issue with humor--a satire on normal, everyday problems like going to the doctor. It can turn a bad experience into something positive that everyone can learn from. It helps to have a vision of differences*

> *about the problem or issue in learning how to resolve the problem. (reflection session notes, June 30, 1997)*

Time Required

Carrying out the health teaching and learning that sought to integrate the physical, the psychological-emotional, and the cognitive embedded in a supportive and empowering community environment took time. We found that three sessions of one and one-half hours each, one to two weeks apart, worked well. Individual classrooms of ten to twenty students each, in which students already knew each other, provided an atmosphere where students were likely to feel comfortable and safe. Individual classrooms also had the advantage of a common language and literacy level. In the cancer education program, well over twenty-five direct teaching hours were required, all of which took two or more planning and follow-up hours for each session. The program extended over six months when our learning time and evaluation activities are included. The amount of time required for the family violence program was similar. However, our learning time was much greater (four months) because we had to research the topic ourselves and we had to allow more time for us to become comfortable with the information and process.

Voice, Changing Perceptions of Self and Self in Relationship to Others, and Action

Insights from our Evaluations

From the survey we did after the cancer education program, we learned that the information was not new to over forty percent of the students. However, they told us almost unanimously that learning about early detection of breast, cervical, and testicular cancer was important to them. They affirmed the importance of being able to choose the health topic to study through the community "dot" vote. They also affirmed that Operation Bootstrap was a good place to learn about health and that learning from other students was a good way to learn about health. Over seventy percent strongly agreed and thirty percent somewhat agreed that they understood about these cancers better than before. Well over eighty percent reported doing breast self-examinations and having gone for PAP tests. Sixty-eight percent of the men reported doing testicular self-examinations. Going for mammograms was reported at slightly over fifty-five percent (most Operation Bootstrap students are in their early thirties so one would not expect to see a high incidence of mammograms that are recommended for age forty and up).

> *The most exciting surprise from the survey was the extent to which Operation Bootstrap students were sharing the information learned in the classroom with family, friends, neighbors, and in community groups.*

The most exciting surprise from the survey was the extent to which Operation Bootstrap students were sharing the information learned in the classroom with family, friends, neighbors, and in community groups. In the survey, nearly seventy percent of the Operation Bootstrap students told us that they had shared their learning about early detection of breast, cervical, and testicular cancer with family, friends, neighbors, and with people in their community groups, such as churches, social clubs, and cultural clubs. The details of what was shared is not known. However, there were anecdotal reports of showing others how to do breast self-examinations and the small models distributed to practice at home were in big demand. Through informal conversations with team members, students also told us about insisting their wives, mothers, aunts, and other women in their families take advantage of the community screening and follow-up programs. They also told us that they felt proud and powerful to have this important information that would help their families and others dear to them.

Many other social changes around health were occurring within Operation Bootstrap. During group and individual interviews with teachers we learned that the information was the subject of an on-going discussion in the classrooms. Students encouraged one another to seek medical screening tests and when tests (particularly PAP tests) came back abnormal, they were able to talk about it in class and get support. The health educator was frequently called on to explain test results. Team members themselves occasionally took students for medical tests when they had discovered breast lumps, but were afraid to seek medical assistance because they lacked insurance and were limited English. Within the team, we were encouraging each other to take care and action ourselves. One of the teachers discovered a lump in her breast and the entire learning center held its collective breath until her biopsy showed negative results. When it was discovered that one of the students actually had breast cancer, her classmates and we in the team gave her emotional support and helped to connect her to treatment counseling. There was space and time opening up to talk about health, greater knowledge and comfort levels to discuss specific health issues, and a generalized sense of greater power and control about health.

> *What we had been trying to do was establish a psychologically safe atmosphere where students would gain some knowledge and insights into family violence.*

In the family violence education program, the evaluation was carried out through one-to-one interviews in the native language of the interviewee. The interview questions were developed by the team and the interviews themselves were conducted by team members. We were not interested in ascertaining specific actions, but in gaining a generalized sense of the effects of the program. What we had been trying to do was establish a psychologically safe atmosphere where students would gain some knowledge and insights into family violence. We wanted them to know that it is a wide-spread problem across all sectors of society, exacting an enormous, psychological-emotional toll on the people involved that perpetuates a continuing cycle of power and control. We also wanted students to know the legal dimensions and that there is assistance available--even if that assistance is limited. The program had evolved from Operation Bootstrap students' horror at the abduction of the six-year-old boy and their desire to learn about anti-violence. Did they perceive we had provided them with useful information meaningful for their lives?

It was obvious that the child street-safety part of the program was well received from the turnout of children for fingerprints and videoprints and the eager reception of the dramas about stories strangers use to get children to come with them. The collaboration with the police for fingerprinting had resulted in highly positive interaction between the Operation Bootstrap students and the community police department. Moreover, we already knew from our in-class dramas about the effects of witnessing violence in the home on children and of man-woman violence that students were actively engaging in discussion about the issues in family violence. Each drama was followed by discussions in small groups and the discussions were recorded on newsprint, then summarized, given back to the classes, and posted on the community bulletin boards. Many students demonstrated great insight and understanding into the complexities of family violence and were knowledgeable about community resources for assistance. Economic circumstances and cultural context were seen as being primary factors in keeping women trapped in violent homes as well as the isolation that often surrounds an abusive situation. The family violence teaching and learning opened up space to help break the isolation for both students in violent homes and for their families, friends, and neighbors of the students. It was notable that a number of students indicated that they would no longer stand passively by if they knew family

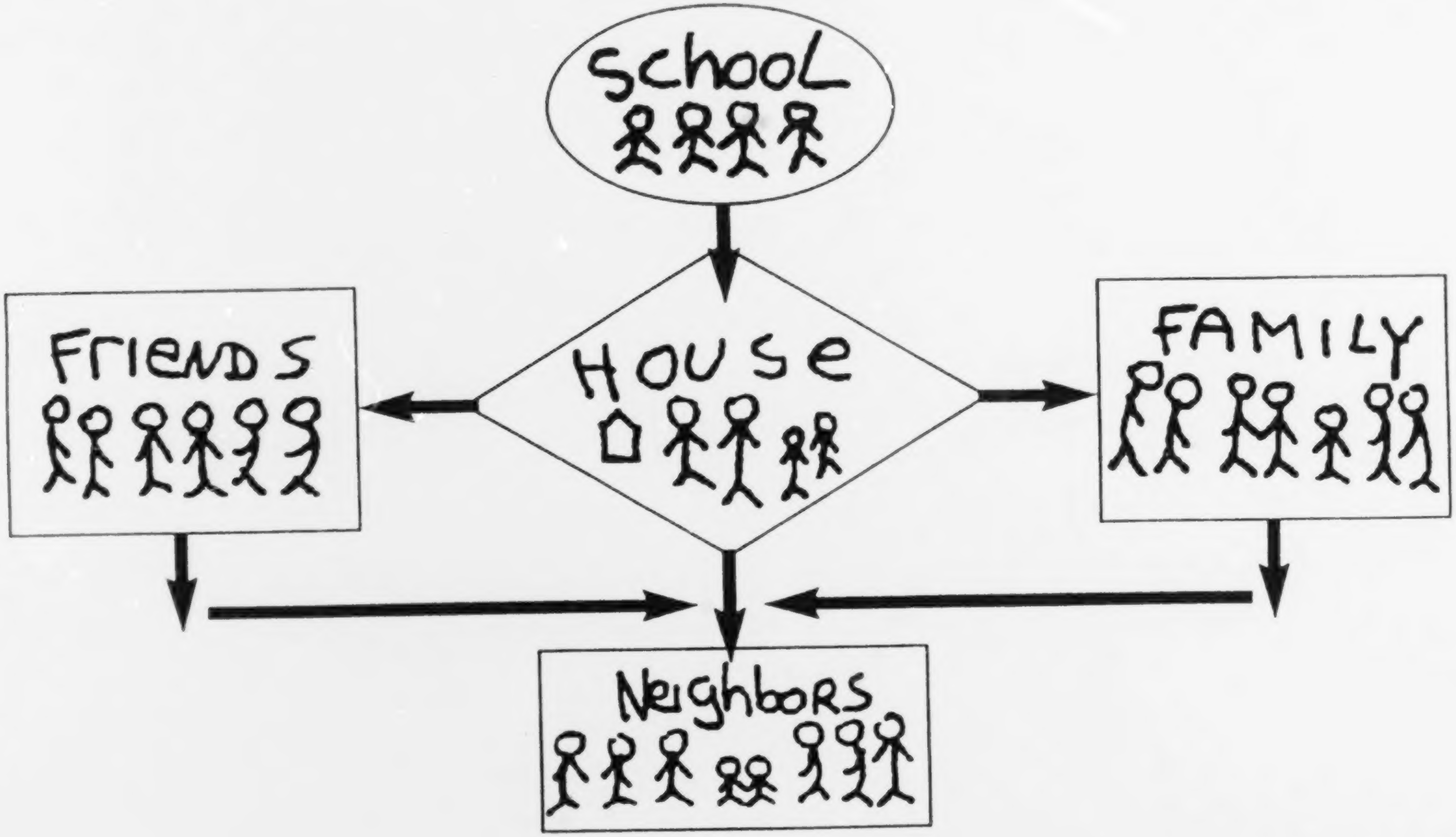
> *It was notable that a number of students indicated that they would no longer stand passively by if they knew family violence was occurring within their family, or with friends and neighbors.*

violence was occurring within their family, or with friends and neighbors. They would call the police or a social service agency or get someone to help them intervene.

We in the team and the Operation Bootstrap staff also noted that the resource board that the team put together to list appropriate agencies and their phone numbers, and the help available within the program, was frequently visited. Students often requested multiple copies of the written handouts from the classes, particularly the one listing the social service agencies such as the Women's Resource Centers, or programs such as HAWC (Help for Abused Women and Children).

As with the cancer education program, we learned that there was great diffusion of the information to families, friends, neighbors, and community groups, such as churches and cultural organizations. In the interviews, over seventy-five percent of the students indicated that they had shared the information, often with several different people. Most of the sharing was with friends and family. It was clear there was great pride and sense of personal power in having knowledge and information that would help family, friends, neighbors, and community. One team member captures how information gets diffused in the drawing on the following page.

How information is diffused


School
Friends
House
Family
Neighbors

**Graphic Created by Elsa Reynoso,
Student Action Health Team**

Well over one half of the students said some of the information was not new, but that it was important to hear it again because it "helps you realize what you already know" and "adds new information." We knew family violence was a reality in many students' lives, and in many of the interviews the students said, "I have seen this my whole life." The program gave them a chance to take a psychological step back, to know that the abused person is not alone, and there is help available.

Drama was seen as "getting the point across," "making me see, even though I do not have much English," "helping you understand, even if you don't get all the words," "holding attention," and was "funny sometimes."

Our great fear that the program would stir up anger, turmoil, and despair that had no place to go and be more destructive than helpful was not realized. The dramas, the small group discussions, and the emphasis on resources available built safety walls around the topic. In the one instance where a woman student broke down sobbing after a man-woman violence drama, her classmates, the staff, and the team physically and emotionally enfolded her until a counselor was reached. Students were clearly trying to support one another emotionally, without intruding on each other's privacy.

The session about the effects on children of witnessing violence in the home had special significance for some students. In their interviews they said how that session further validated their decision to leave violent homes. For many students, and for the team and staff, effects on children was a new area of information--one that we had to laboriously search out--but a critical pathway to meaningful connections in people's lives. It was easy for some to dismiss man-woman violence as a culturally acceptable phenomenon. It was much more difficult to dismiss the devastating effects on the children who witness this violence and how it sets up the next generation to continue the cycle of abuse. When violence is modeled as a way to solve problems or control another person in the home, children internalize the message. One student noted that it "makes us conscious of our conduct as parents."

The dramas were the most popular of the teaching and learning activities, mentioned in well over one-half of the interviews. Drama was seen as "getting the point across," "making me see, even though I do not have much English," "helping you understand, even if you don't get all the words," "holding attention," and was "funny sometimes." Students also appreciated the opportunity to process the dramas in small group discussions, saying they thought the "writing down" (on newsprint) activity was important to furthering their understanding and communicating good ideas from other students. Several students commented that the team should go to different places to teach because they have important information to share and know how to share and teach it. They said "regular" schools should teach like this.

In the interviews, students unanimously affirmed the importance to them of the health learning and that they considered Operation Bootstrap to be a good place to learn about health. They saw the health teaching and learning sessions as not only giving them important health information for their everyday lives, but adding to their language and literacy learning. Some of the ways they saw their language and literacy learning being supported was by a) broadening vocabulary, b) improving reading and writing, c) helping understand spoken English, d) providing another way of learning and a break from other learning, and e) small group discussion deepening your understanding of both the language and the topic.

The Operation Bootstrap teachers saw that the topic of health was a great energizer and motivator for language and literacy learning. Moreover, as language and literacy skills developed, the dialogue about health was facilitated and the processes became interactive.

Language and Literacy Learning Facilitates the Dialogue about Health & Health Catalyzes the Motivation for Language and Literacy Learning

In the beginning English classes, we used to teach in native languages to the extent that the team had the language capacity. Both the team and the teachers felt that understanding the information was more important than English language development. The team had ability in six languages--Creole, English, French, Russian, Spanish, and Vietnamese. However, several of the beginning English classes had more than ten language backgrounds, so we were not able to address all the language needs. Translating also took enormous amounts of time. Many classes elected to struggle through with English, with team members explaining in native languages informally when students indicated they did not understand. Operation Bootstrap students were eager to improve their language skills and embraced opportunities to listen and to speak.

The team was very much a role model for English language students to speak. One teacher noted that:

> *The fact is that the student action health team is a model for having the courage to speak, even if language is not perfect...the permission to speak without worrying about grammar etc. I see so many students who put their life on hold. They say `when I learn English I will...' I am so impressed with the difference in [one team member]. She used to be obsessed with the imperfection of her [English] language. Now she knows that what she has to say is more important than the way she says it. (interview, February 24, 1997)*

This team member frequently talked in team meetings about how her English language skills had taken quantum leaps forward when she became intent and focused on understanding and being understood. In fact, discussions by all the team members from other language background saying how the team experience had facilitated their language development is threaded throughout my field notes and notes from reflection sessions. A teacher notes:

> *There is nothing like a small group experience, like the student action health team or the student council, that arises around a purpose and a focus where all of the cognitive stuff happens peripherally. When you are not focusing on learning goals, learning sneaks up on you. (interview, February 24, 1997)*

For the Operation Bootstrap students, the subject of health was seen as a great catalyst in their language and literacy development. One teacher articulated the thoughts of many of the Operation Bootstrap teachers in the following statement:

> *Health is a place where students are willing to push the limits of their communicative ability. It is a topic with an immediate link to reality--closer to the bone--as opposed to a topic like civic stuff for citizenship. That's not the kind of stuff where we are going to spend a lot of time in [trying] to be communicative--making ourselves understood. But when I did follow-up on the child street-safety session [with my beginning English class], I was impressed with their willingness to `language it out'--how hard they worked to exchange information.*
>
> *Health is not a topic to dry up fast. It's personal, not re-learning. It's new information well within your grasp...so engaging, that even though struggling with language, will keep at it. [It] frees you from dependence on the teacher...you are learning 'tools for life'...and building vocabulary that gives you control around an important life topic. Health is important to everyone and a universal experience that cuts across everyone's concerns. (interview, March 11, 1997)*

Certainly it was clear that in the small group discussions after each of the violence dramas, the language students were pushing themselves hard to understand and to be understood in the common language of English. They were eager to share their ideas and knowledge of resources and to practice articulating and writing those ideas down. In the general adult basic education and General Educational Development classrooms, the group discussions also provided valuable practice in articulating ideas clearly and getting them written down.

The health topics we covered in our programs were of such importance to Operation Bootstrap students that teachers could productively use the handouts, stories, and vocabulary lists we furnished in any number of ways. As teachers noted, they are there before, during, and after the team did the health sessions. Vocabulary building, follow-up reading and writing, note-taking exercises, questions, and discussions with partners or in small groups, and games and puzzles were all ways teachers could and did connect literacy development skills with the health content. For example, one beginning English class reenacted the dramas, taking photographs that they then labeled for a picture-word matching activity, to reinforce their vocabulary building.

The strongest and most direct connections to in-classroom language and literacy learning was made in the English language classes, the weakest connection with the

General Educational Development (GED) classrooms where students tend to be fixated on preparing for the GED test. The presence of pre-prepared literacy development materials, available through Project HEAL's (Health Education in Adult Literacy) Breast and Cervical Cancer Kit, allowed stronger connections during the cancer education program than in the family violence program.

It was not, however, our intention to develop specific skill-focused connections to language and literacy development with our health teaching and learning program. We wanted to provide basic materials to teachers so they could follow up in classroom activities. We did not see that every piece of the health information should be turned into a specific literacy skill exercise. In fact, there is a need to be cautious about overdoing the connection to literacy skills development. The intensity of interest and the motivation to learn about health topics greatly enhanced students' desire and willingness to be communicative--to listen, to understand, to be understood, and to read and write around health. Focusing too specifically in language and literacy activities has strong potential to drown the energy and spirit in a sea of unrelated and decontextualized skill areas.

Learning that goes beyond traditional language and literacy activities emerged as an important avenue to explore. Related learning activities, such as looking up health information in the library, using the Internet for finding health information, learning how to evaluate information, reading health statistics, graphs, and charts, and researching community resources all develop important critical thinking skills and literacy behaviors. In fact, those were the type of learning activities that we in the team were undertaking for ourselves.

Where are we now and where are we going?
The Student Action Health Team-- A Summary

Our learning was increasing by leaps and bounds, far beyond the health topics themselves. Not only were we learning about specific health issues, but we were learning where to get the information, how to evaluate it, and how to modify it into simpler terms and concepts. We were learning how to work cooperatively to design, implement, and evaluate health programs, and to research community resources. We were learning how to explain what we had done and what we learned from the process to people outside of Operation Bootstrap in the wider health and literacy worlds.

Presenting our work to others and writing about our work for others contributed greatly to our growth as communicators. We developed a deeper understanding of the meaning of our work when we had to translate our knowledge into concepts that would relate to different informational needs and interests. We were shifting our relationship to both health information and the ways to communicate health information, gaining the confidence and skills to facilitate a different conversation about empowerment health education.

Our intention became to put both ourselves and the Operation Bootstrap students in a different relationship with health issues.

We started with trying to address a problem in health education and promotion. As we saw it, the problem was that low literacy adults do not benefit from existing health education and promotion because the education is disconnected from their everyday health concerns and questions. There are few health-education opportunities that provide psychologically safe and empowering environments for learning while simultaneously attending to issues of literacy level. We placed the Operation Bootstrap students' health concerns, and their understanding and connection to those health concerns, central to our entire process. In doing so, we developed teaching and learning programs that moved beyond a set of instructional strategies to a model and a set of principles that could guide the work of others. Our intention became to put both ourselves and the Operation Bootstrap students in a different relationship with health issues. Through accessing and understanding current information, knowing the vocabulary, learning to ask questions about it, exploring its meaning for the inquirers, their families and the community, supporting voices that reflect different perspectives or alternative ways of thinking about the issue, we were attempting to develop a greater sense of power and control about health. The power and control would, we believed, provide for more informed health decision-making, a greater understanding of personal rights and responsibilities in accessing health care information and services, and set the stage for individual and collective action around health issues. For the Operation Bootstrap students, this power and control was developed through their engagement with new specific health issues they chose for their health learning. For us in the team, the power and control was to introduce a new approach to empowerment health education that drew on the naturally occurring social webs of adult literacy classrooms. In the process, we discovered that the work was a grand demonstration and validation of the concept of literacy education as contextualized in learner's lives and supporting their life roles. We were creating knowledge, not only about empowerment health education and promotion, but about literacy education and how the two educational strands interact.

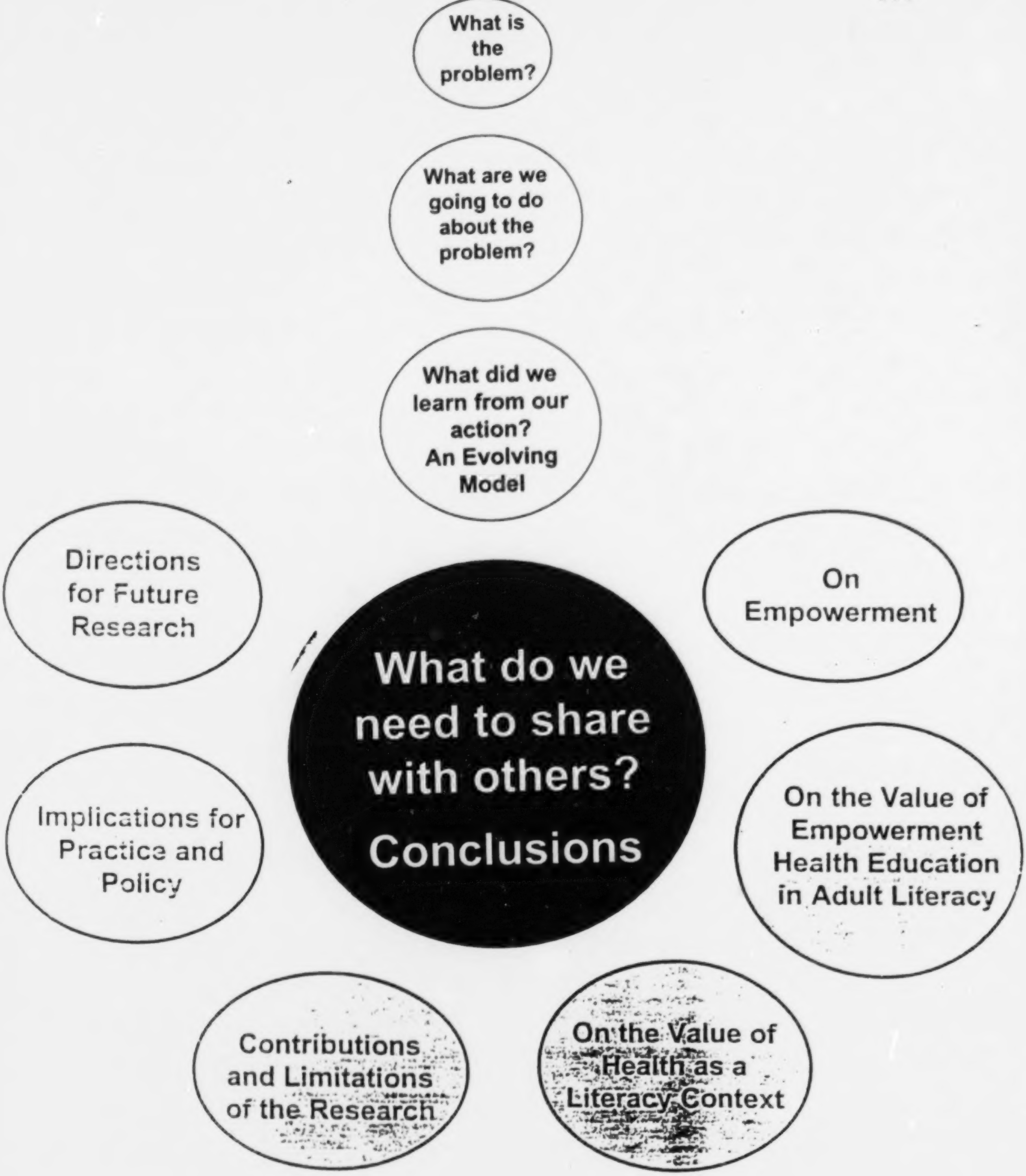
> *...we discovered that the work was a grand demonstration and validation of the concept of literacy education as contextualized in learner's lives and supporting their life roles.*

In taking the work to the outside and attempting to influence policy and funding decisions, we have engaged and are currently engaging in a myriad of activities. Throughout the research process, we have presented at state-wide conferences, written articles for publications of the New England Literacy Resource Center, and developed resource notebooks about our work to assist other literacy practitioners and students. Through our presentation in Washington D.C. (May, 1997) to policy makers in the national legislature and major health institutions, such as the Centers for Disease Control and the National Institute for Health, we were attempting to influence national policy and funding development. This publication centers on the voices of the team and of the Operation Bootstrap students and what knowledge we created when we entered into a partnership for empowerment health education.

Within Massachusetts, the team has entered into mentoring relationships with two adult literacy programs who are undertaking health and literacy work for the first time. The mentoring program is supported financially by the Massachusetts Department of Education, and has included working directly with the individual programs and being presenter-participants in a full-day session on health and literacy at the annual state-wide conference (October 1997). We are also in dialogue with students at two other literacy programs in the western part of the state over our mutual interest in connecting the health and literacy work with economic development projects. The latter evolved out of our family violence work from which we concluded that economic circumstances was one of the greatest factors in keeping women and their children trapped in violent homes.

During the research process, I had committed to partnering with the team to share power, as they committed to sharing power with the Operation Bootstrap students. I had also made the commitment to keep team members involved in taking the work to the outside in a continuation of that power-sharing. I have strived to maintain those commitments, although the process has been far from perfect. I have also struggled with the power implications of my individual writing about a collective research process.

These struggles have led me to examine the power dynamics and issues in the participatory action research process generally and in the context of health and literacy linked education particularly. While the analysis is too lengthy to be included in this publication I would be happy to share it with interested practitioners. Please contact me directly at the addresses supplied on the title page for a copy of the report entitled "Power and Participatory Process".


What is the problem?
What are we going to do about the problem?
What did we learn from our action? An Evolving Model
Directions for Future Research
On Empowerment
What do we need to share with others?
Conclusions
Implications for Practice and Policy
On the Value of Empowerment Health Education in Adult Literacy
Contributions and Limitations of the Research
On the Value of Health as a Literacy Context

Section IV

What did we learn from our action research?

Students saw health as an important topic

Leadership vehicle for students

Students listened to and trusted student teachers

Social space opened to talk about health

Adult literacy programs a good place to learn about health

Health topics facilitated and motivated literacy learning

Students saw information as useful and meaningful

Students took action:

- shared information
- went for tests
- used community resources
- supported each other

Students understood information

This learning process forever shifts a person's knowledge and skills for dealing with health issues in their lives.

BEST COPY AVAILABLE

Graphic created by Marcia Drew Hohn, 1997 NIFL Literacy Leader Fellow, (978)688-6089

Conclusions

This project set out to learn about embedding empowerment health education in adult literacy through the process of actually doing it. The research process was participatory in nature and was carried out in a collaborative, power-sharing partnership with a student action health team at an adult literacy program.

Engaging in a continuous cycle of reflection and action, we went through a four-step process common to participatory action research in which we a) identified the problem(s) to address, b) took action to address the problem(s), c) synthesized our learning from action, and d) determined what we needed to share about our learning.

This section describes our conclusions we believe need to be shared about

- Empowerment and knowledge creation
- The value of empowerment health education in adult literacy
- The value of health as a context for language and literacy learning

Empowerment

This research has clearly demonstrated that people feel powerful, or empowered, when they are partners in the process and when they are able to see change, both within themselves and in desired directions outside of themselves. The power-sharing approach in the research project enabled the voices of the student action health team and the students whom they served to be heard and acted upon.

Voice is being able to articulate your beliefs, interests, and concerns in ways that can be heard by others, moving to hearing conversation among other voices, to entering the conversation, and ultimately to be able to help shape the conversation. However, voice alone, disconnected from action, has limitations. The active and participatory nature of the work of the student action health team, coupled with periodic reflection about what we had learned and what happened to us in the process, confirms the importance of the voice and action / interaction. It also affirms the importance of deliberately constructing environments that support and enhance voice and action through power-sharing processes and relationships, environments in which people can develop their own sense of agency and find their own action routes to power and control in their lives.

The Value of Empowerment Health Education Embedded in Adult Literacy

Health education needs to be more than simply reaching people with a particular health message or a particular piece of health information. The view of addressing the health education needs of low literacy groups through simply rewriting existing materials at a simpler language level is exceedingly limited. Information is only one piece of a process that needs to include community context, participation, and support. Within adult literacy programs, there is the potential for the luxury of time, and an environment conducive to participatory process, where adult literacy learners and staff can work together with community health educators to design and implement health teaching and learning programs. The programs can address both the health and the language-literacy learning needs of adult literacy students and can catalyze one another in a process of mutual enhancement.

> *It provides tools for lifelong learning around health that can be applied in a myriad of settings, both within health education and in the broader world.*

The present research has demonstrated the power of the participatory, empowerment approach to health within adult literacy programs. This approach supports the community's self-identified needs and interests and provides appropriate teaching and learning approaches to address those needs and interests in ways that enable participants to connect the health learning to their everyday lives and the lives of their families, friends, and communities. It provides an environment in which people can develop new beliefs about their efficacy to influence their personal and social worlds and which builds their social capacity and confidence to connect to others in an ever-widening web of social networks. It provides tools for lifelong learning around health that can be applied in a myriad of settings, both within health education and in the broader world.

Overall, the research has provided a rich demonstration and validation of the community-based empowerment model of health education--a model that provided a pivotal starting place for the research. In the empowerment model, the focus is on facilitating individual and community choices through providing information in a context that allows for values clarification and practice in decision-making and community organizing skills through the use of nontraditional teaching methods. The processes and findings of the research support and affirm these concepts that form the empowerment model.

Empowerment health education embedded in adult literacy provides a way to reach out to low literacy communities that have been disconnected from traditional health education and promotion efforts. It engages them in a dialogue about health in a social space where their psychological-emotional and physical safety is maintained and their health needs and interests are central to the process. It provides an open forum to dialogue and share about health, and for community support and encouragement to take action. It can be an effective environment for prevention messages and for fostering the ideas of taking care of yourself, helping to dissipate fears through knowledge, skills and tools, and developing a knowledge of options. It sets the stage for individual and collective action. Jean-Marie Aubin (1997) articulates how the stage is set in her words:

> *I learned that health starts with the personal (how am I affected?), leads to the social (how does it affect others?), and continues to the political (what can I do to change the situation or circumstances?). The subject of health connects the personal with the social and the political. (p. 3)*

The diffusion of health information beyond the classrooms and program walls was a significant finding of the research. The tremendous energy that accompanies health learning increases its flow to families, friends, and communities and builds on the support networks those relationships provide. It expands the walls of the literacy program out, melding them with the community.

In a health-care environment in which people are expected to be active participants in their health care, the potential of new pathways to develop a sense of power and control about health among a frequently disenfranchised group should be of great interest to health educators. The public health care world is under intense pressure to find better ways to communicate effectively with low literacy populations. The extent of low literacy within the United States, affecting ninety million people, coupled with legal mandates to demonstrate clear communications between health providers and recipients and the economic pressures within managed care to promote understanding about disease prevention, provide compelling forces to find new ways to communicate about health. There is a need to be liberated from defining the problem of low literacy and poor health connection according to old solutions. The research has demonstrated that embedding health education in adult literacy in an approach where active learning is connected to the realities and concerns of people's everyday lives, supported through the naturally occurring social webs of literacy classrooms and processes that create and sustain power-sharing, provides a rich and meaningful learning forum for health. Empowerment health education in adult literacy provides another avenue in the broad repertoire of approaches needed to address the social dilemma of the low literacy, poor-health and early-death connection and the social justice issue inherent in this dilemma.

The Value of Health as a Context for Language and Literacy Learning

The topic of health as a context for language and literacy learning provides a holistic structure through which to learn. Health learning that actively engages people's physical bodies, minds, and psychological-emotional essences embodies the whole person. When the whole-person approach to health is combined with a participatory approach in which power is shared and multiple power-sharing relationships emerge, a vigorous and dynamic learning medium is established. Health as a context for language and literacy learning, then, can generate great energy and an environment where learners are willing to push the limits of their communicative abilities to be heard and to understand. Health provides a rich forum, meaningful for people's lives and the lives of their families and communities. It provides compelling motivation to engage with language and literacy learning. In turn, language and literacy learning motivates and facilitates the dialogue about health. The processes of health education and literacy education enhance and reinforce one another.

The present research also provides important evidence that embedding health education in adult literacy can provide new avenues for development of student leaders and peer educators who can carry their learning and skills into other arenas in their lives.

It provides opportunities to nurture and nourish the capacity of all participants to become and stay informed about health, to articulate opinions and ideas, and to work together to support individual and collective action.

When adult literacy education is understood to be in the context of adults' lives, that the context of their issues, problems, aspirations, skills, cultures, and languages creates the basis for literacy work as well as the tools to engage in it, then health provides natural content and context. In fact, the entire research project was a grand demonstration and validation of the concept of literacy education as contextualized in learners' lives, in support of their life roles, and in support of them as whole people.

Contribution and Limitations

To my knowledge, this is the only study of empowerment health education within adult literacy in the United States that has brought a systematic and intentional research framework that embodies the authentic voice of the target group. This is emergent knowledge about a new and understudied area of educational endeavor. As such, it should be of great help to guide literacy and health practitioners and students undertaking similar work as well as policy makers and funders who may initiate and/or support the work. It should also be of assistance to researchers looking to document key program elements and to identify additional questions needing investigation.

However, this was one study conducted at a single site with a particular group of learners in a particular program environment, bounded in a particular time and space. It was conducted in a state that has a highly developed adult literacy system with significant resources supporting the system. It was conducted within a unique adult literacy program that attempts to be participatory at all levels of the organization and prioritizes the development of student leaders. The student action health team with whom I carried out the research remained composed of all women throughout the two years which undoubtedly affected perceptions of the problems, as well as development of the actions to address those problems and the learning from the actions. These are not environments and compositions likely to be found across the diversified national landscape of adult literacy education. However, the model and principles are not meant for direct replication or as dictates for future work. They are meant to provide a basis on which other work and studies can proceed. Much more needs to be learned about the experience of embedding health education in a variety of different adult literacy settings to broaden the scope of knowledge.

Implications for Policy and Funding

- Adult literacy programs, including English language, family literacy, general educational development and basic literacy programs, provide ideal sites for reaching out to low literacy communities that have been disconnected from traditional health education and promotion efforts. Adult literacy programs provide a rich environment for messages about prevention and early detection as well as fostering the ideas of taking care of yourself. They provide the time and expertise for empowerment health education and a rich environment for collaboration between adult literacy and public health agencies. **Public health and adult literacy policy-makers and funders need to provide language in legislation and requests for proposals that invites and supports collaborative programming and equal partnership.**

- Empowerment health education enhances the potential for sustained individual and collective action about health. However, this type of education, which values and supports participation, encourages leadership development and honors diversity, takes time. **Policy and funding needs to recognize that this is at least a three- to five-year process.**

- Health education in adult literacy is a new area of work; both adult literacy and health educators need to have continuing support as they connect their practices. **Public health and adult literacy education policy and funding needs to provide**

opportunities for the health and literacy education communities to come together for program and staff development.

- Further research is needed to pilot the model and its guiding principles in other settings that reflect the varied national landscape of adult literacy. The relationship to other major literacy initiatives, such as family literacy and civic participation, also needs to be investigated. **Both public health and adult literacy policy and funding need to provide for continued research.**

Directions for Future Research

In addition to the need for enlarged experience with health education in adult literacy, there are some specific areas that this research has identified as needing further investigation. One such area is the relationship of the health and literacy work to the initiatives currently underway to support the development of family and intergenerational literacy. Since the students in this study clearly identified their health learning as directly connected to the well-being of their families, the linkages between the two areas need to be identified and addressed. Similarly, the connection to initiatives in civic participation needs to be investigated. The development of student health teachers expanded their sense of leadership and efficacy in working with community groups. Does this experience carry over into greater civic participation and if so, in what ways does this happen?

Diffusion of health information into families, neighborhoods, and communities was clearly a strong finding in this research study. Much more needs to be known about this diffusion. What was being shared, with whom, and for what purpose? What were the pathways and what were the outcomes of diffused information for both the giver and receiver of the information?

The research also suggests that there may be an important trinity in development of voice accompanying learning about the body and becoming more fully literate. This would further suggest that attempts to move persons into voice without enabling them to have control over their bodies or information about their bodies would be less productive. There appears to be something unique, special and organic about ways into literacy through the body that need further investigation. Pincus and Callahan (1995) also call attention to the need for further investigation of mind-body interactions as they pertain to people's health understanding and behavior and ultimately, health status. The relationships between voice, the body and literacy development are far from clear, however, and there needs to be an exploration of whether there are significant enough relationships to warrant exploration of their nature.

I look forward to a continuing dialogue about investigation of these questions with great hope and excitement.

Some Suggestions for Practitioners:
Getting Started With Linking Health And Literacy Education

For Adult Literacy Educators

1. Start small by introducing a health topic in which your students have indicated an interest. Nutrition and stress are popular topics with adult literacy students.
2. Have students research various aspects of this health topic through library, health agency and internet resources (some resources are cited below).
3. Let your students teach each other and you about what they have learned.
4. Access sources cited below for teaching materials, health stories by adult literacy students and lesson plans developed by literacy teachers and students.
5. Call local community health centers for assistance with specialized materials and health educators as appropriate. You can find centers in your local phone book or call the state public health office.
6. Consider developing a student health team in your classroom or program.

For Public Health Educators

1. Find out about your local adult literacy programs through contacting your State Literacy Resource Institute (SLRC). All SLRC's have home pages on the National Institute for Literacy website at http://novel.nifl.gov.
2. Call or visit these programs to explain your health education services and increase your visibility and access.
3. Visit these programs to learn about the health concerns among the adult students.

4. Work collaboratively with the program, teachers and students to see where effective connections might be made between health and literacy education.

For Both Adult Literacy and Health Practitioners

- **Join the health and literacy listserv discussion sponsored by the National Institute for Literacy**. This listserv has about 250 practitioners from both public health and adult literacy who exchange ideas, materials, resources and make personal connections about health education for low literacy groups. You need only have email to subscribe. **To subscribe, send a message to listproc@literacy.nifl.gov with the following message in the text of the message: Subscribe nifl-health firstname lastname** (example -- subscribe nifl-health sue smith).

- **Access resources for low literacy health materials and/or programs at: http://hubl.worlded.org** (This site has many links to other sites and is a specialty site for low literacy health materials developed by adult literacy students on-line).

- **Email: hlphpc@libertynet.org** for a list of low literacy health materials for specific chronic health conditions (Health Literacy Project at the Philadelphia Health Promotion Council).

- **Call World Education in Boston (617-482-9485)** for *Ideas in Action: A Guide to Participatory Health Education* by Morrish and LaMachia and for *Project HEAL* (early detection of breast and cervical cancer for low literacy audiences) materials.

- **Take advantage of continuing professional development opportunities on connecting health and literacy education.** The National Institute for Literacy's listserv is a good place to learn about these conferences and seminars.

REFERENCES

Adams, D.L. (Ed.). (1995). **Health issues for women of color.** Thousand Oaks, CA.: Sage.

Adelson, B. (1993). **Legitimizing our action knowledge.** In L. Alcoff & E. Potter (Eds.), Feminist epistomelogies (pp. 85-89). New York: Routledge.

Airhihenbuwa, C.O. (1994). **Health promotion and the discourse on culture: Implications for empowerment.** Health Education Quarterly, 21(3), 346-351.

Alcoff, L. & Potter, E. (1993). **Introduction: When feminisms intersect epistemology.** In L. Alcoff & E. Potter (Eds.), Feminist epistomologies (pp 1-14). New York: Routledge.

Anderson, R., Dames, J.K., Keckbusch, I., McQuien, D.V. & Turner, J. (1988). **Health behaviour research and health promotion.** Oxford: Oxford University Press.

Apel, K.O. (1980). **Toward a transformation of philosophy.** London: Routledge and Kegan Paul.

Argyris, C & Schon, D.A. (1989). **Participatory action research and action science compared.** American Behavioral Scientist 32(5), 612-623.

Arnold, R., Brandt, D. & Burke, B. (1985). **A new weave: Popular education in Canada and Central America.** Toronto: CUSO Development Education.

Arnold, R., Burke, B., Carl J., D'Arcy, M. & Thomas, B. (1991). **Educating for a change.** Toronto: Between the Lines Press.

Aubin. J.M. (1997). **Who me? A health educator?** The Change Agent, Issue 4. Boston: New England Literacy Resource Center.

Auerbach, E. (1992). **Making meaning, making change.** Washington, D.C.: The Center for Applied Linguistics.

Bean, R. et al. (1990). **The beginning with books gift book program: Effects on family and child literacy.** ERIC Document #ED329926

Beder, H.W. (1991). **Adult literacy: Issues for policy and practice.** Malabar, FL: Krieger.

Beder, H. (1991). **The stigma of illiteracy**. Journal of Adult Basic Education 1 (2).

Belenky, M.F., Clinchy, B.V., Goldberger, N.R. & Tarule, J.M. (1986). **Women's ways of knowing.** New York: Basic Books.

Bernstein, E. (1994). **Empowerment forum: A dialogue between guest editorial board members.** Health Education Quarterly, 21 (3), pp. 281-294.

Braithwaite, R.L. (1994). **Empowerment forum: A dialogue between guest editorial board memebers.** Health Education Quarterly, 21 (3), pp. 281-294.

Capra, F. (1982). **The turning point.** New York: Simon & Schuster.

Chen, I. (1994, March). **Teach your patients well.** Hippocrates, 32-37.

Chisman, F.P. & Associates (1990). **Leadership for literacy.** San Franciso: Jossey-Bass..

Clenland, J.G. & Van Ginniken, J.K. (1988). **Maternal education and child survival in developing countries: The search for pathways of influence.** Social Science Medicine, 27(1), 357-368.

Cochran-Smith, M. & Lytle, S.L. (1993). **Inside/outside: Teacher research and knowledge**. New York: Teachers College Press.

Cochrane, S.H., O'Hara, D.J., & Leslie, J. (1980). **The effects of education on health.** World Bank Staff Working Paper 405. Washington D.C.: World Bank.

Colquhoun, D. (1996a). **Policy analysis and the health promoting school in Austria: A critique.** Unpublished manuscript.

Colquhoun, D. (1996b). **Researching with young people on health and environment: The politics of self-esteem and stress.** Unpublished manuscript.

Davis, T.C., Meldrum, H., Tippy, P.K.P., Weiss, B.D. & Williams, M.V. (1996, Oct. 15). **How poor literacy leads to poor health care.** Patient Care, 94-108.1.

Doak, C.C. & Doak, L.G. (1993). **The literacy challenge in diabetes education: So that clients may understand.** Diabetes Care and and Education, 14 (2), 9-11.

Doak, C.C., Doak. L.G. & Root, J.H. (1996). **Teaching patients with low literacy skills**. Philadelphia: J.P. Lippincott.

Elden, M. & Levin, M. (1991). **Cogenerative learning: Bringing participation into action research.** In W. F. Whyte (Ed.), Participatory action research (pp. 127-142). Newbury Park, CA: Sage.

Fals-Borda, O. & Rahman, M.A. (1991). **Action and knowledge: Breaking the monopoly with participatory action research.** New York: Apex Press.

Furnas, S., McClellan, E., Haywood, J., Ohene-Frempong, J. & Taylor-Watson, M. (1996). **Literacy, health, and the law.** Philadelphia: Health Promotion Council.

Fingeret, H.A. (1991). **Meaning, experience and literacy**. Journal of Adult Basic Education, 1 (1).

Fingeret, H.A. (1990). **Changing literacy instruction: Moving beyond the status quo** (In Leadership for Literacy). San Francisco: Jossey-Bass.

Freire, P. (1985). **The politics of education: Culture, power, and liberation.** South Hadley, MA: Bergin-Garvey.

Gaventa, J., John, P. & Bell, B. (Eds). (1991). **We make the road by walking: conversations between Paulo Freire and Myles Horton.** Philadelphia: Temple University Press.

Gaventa, J. (1980). **Power and powerlessness: Quiescence and rebellion in an Appalachian valley.** Urbana: University of Illinois Press.

Geertz, C. (1973). **The interpretation of cultures: Selected essays.** New York: Basic Books.

Giachello, A.L. (1995). **Cultural diversity and institutional inequality.** In D.L. Adams (Ed.), Health issues for women of color. Thousand Oaks, CA: Sage.

Glanz, K., Lewis, F.M & Rimer, B.K., (Eds).. (1990). **Health behavior and health education: Theory, research and practice.** San Franciso: Jossey-Bass.

Geissler, B. (1994). **Literacy-health partnerships that work.** Adult Learning 5 (6), 21-22, 26.

Greenwood, D.J., Whyte, W.f. & Harlavy (1993). **Participatory action research as a process and as a goal.** Tavistock Institute of Human Relations , 46 (2), 175-192.

Grosse, R.N., Auffrey, B. (1989). **Literacy and health status in developing countries.** Annual Review of Public Health, 10, 281-297.

Guba, E.G. & Lincoln, Y.S. (1994). **Competing paradigms in qualitative research.** In N.K. Denzin & Y.S. Lincoln (Eds), Handbook of qualitative research, 105-117.

Gutierrez, L. (1994). **Empowerment forum: A dialogue between guest editorial board members.** Health Education Quarterly, 21 (3), 281-294.

Hall, B.L. (1981). **Participatory research, popular knowledge and power.** Convergence , 14 (3), 6-17.

Harding, S. (1993). **Rethinking standpoint epistemology: What is "strong objectivity"?** In L. Alcoff & E. Potter (Eds.) Feminist epistemologies, 49-82. New York: Routledge.

Harlan, L.C., Berstein, A.B. & Kessler. L.G. (1991). **Cervical cancer: who is screened and why?** American Journal of Public Health, 81, 885-890.

Heaney, T. (1997). **Adult education for social change: From center stage to the wings and back again.** ERIC Monograph.

Hohn, M.D. (1994). **Staff development for adult literacy.** Report for SABES (System for Adult Basic Education Support) at World Education, Boston, MA.

Hohn, M.D. (1995). **Linking health and literacy education.** Presentation at the American Association of Adult and and Continuing Education, November, 1995.

hooks, b. (1994). **Teaching to transgress.** New York: Routledge.

Horsman, J. (1990). **Something in my mind besides the everyday.** Toronto: Women's Press.

Jackson, R.H. et al. (1991). **Patient reading ability: An overlooked problem in health care.** Southern Medical Journal, 84 (10), 1172-1175.

Joyappa, V. & Martin, D.J. (1996). **Exploring alternative research epistemologies for adult education: Participatory research, feminist research, and feminist participatory research.** Adult Education Quarterly , 47 (1), 1-14.

Kaplan, S.J. & Alsup, R. (1995). **Participatory action research: A creative response to AIDS prevention in diverse communities.** Convergence, 28 (1), November, 1995, 38-56.

Kappel, B. (1988, March). **Literacy and health.** Ontario Medical Review, 55 (3), 42-43.

Kirsch, J.S., Jungeblut, A., Jenkins, L. & Kolstead, A. (1993). **Adult literacy in America: A first look at the results of the National Adult Literacy Survey (NALS).** Washington, D.C.: Department of Education.

Knowles, M. (1989). **The making of an adult educator**. San Francisco: Jossey-Bass.

Koch-Weser, S. (1996). **Posting to the Health and Literacy Discussion Listserv.** Washington, D.C.: National Institute for Literacy.

Kumanyika, K. & Van Horn, B. (1993). **CARDES: Cardiovascular Dietary Education System**. Mosaic 3 (3), 3-5.

Labonte, R. et al. (1994). **Empowerment forum: A dialogue between guest editorial board members.** Health Education Quarterly, 21 (3), 281-294.

Lippin. T & Fingeret. A. (1991). **How adults with limited literacy cope with reading medication labels.** Durham, N.C.: Literacy South.

Lytle, S.L., Belzer, A. & Reuman, R. (1993). **Initiating practitioner inquiry.** Philadelphia: National Center for Adult Literacy Technical Report TR 93-11, November 1993.

Magnani, D. (1995). **Ideas in action.** Conference Proceeding. Boston: World Education, p. 4.

Maquire, P. (1987). **Doing participatory research: A feminist approach.** Amherst: University of Massachusetts, Center for International Education.

Marcus, G.E. (1994). **What comes (just) after "post"?** The case of ethnography. In N.K. Denzin & Y.S. Lincoln (eds.). Handbook of qualitative research, 563-574. Thousand Oaks, CA: Sage.

Martin, P. (1982). **Feminism, criticism, and Foucault.** New German Critique, 27, 3-30.

Massachusetts Attorney General. (1996). **Community benefits guidelines for health maintenance organizations.** Boston: MA Attorney General's Office.

Massachusetts Health Team. (1996). **Mission statement.** Boston: World Education.

Massachusetts Municipal Profiles .(1995). Lynn, MA. Palo Alto, CA: Information Resources.

McFarlane, J. & Fehir, J. (1994). **De madres a madres: A community, primary health care program based on empowerment.** Health Education Quarterly, 21(3), 381-394.

McGrail, L. (1994). **Participatory literacy education graphic**. In Morrish & LaMachia. Boston: World Education. Ideas in Action

McGregor, D.(1960). **The human side of enterprise.** New York: McGraw-Hill, 1960.

Mettger, W. & Ward, A.J. (1993, Nov). **The national work group on cancer and literacy.** Mosaic: Institute for the Study of Adult Literacy, 3,(3).

Merideth, E. (1994). **Critical pedagogy and its application to health education: A critical appraisal of the Casa en Casa model.** Health Education Quarterly, 21 (3), 355-367.

Merrifield, J. (1989). **Putting scientists in their place: Participatory research in environmental and occupational health.** New Market, TN: The Highland Institute.

Miles, M.B. & Huberman, A.M. (1994). **Qualitative data analysis.** Thousand Oaks, CA: Sage.

Miller, J.B. (1982). **Women and power.** Wellesley, MA: Stone Center for Developmental Services and Studies.

Morgan, G. (1983). **Beyond method.** Beverly Hills, CA: Sage.

Morrish, E. & LaMachia, J. (1996). **Ideas in action.** Boston: World Education.

National Cancer Institute (1993). **National workgroup on cancer and literacy interview report.** Washington, D.C.: Office of Cancer Communications.

National Institute for Literacy (1995). **Literacy and adult education in the 104th congress.** Washington, D.C.: National Institute for Literacy.

National Institute for Literacy (1996). **Fast facts on literacy.** Washington D.C.: National Institute for Literacy.

Needlman, R. et al. (1993). **Pediatric interventions to promote picture book use.** ERIC Document #ED346337.

Nelson, L.H. (1990). **Who knows: From Quine to a feminist empiricism.** Philadelphia: Oxford University Press.

Ontario Public Health Association (1990, 1992). **Literacy and health project: Phase one and phase two reports.** Ontario: Public Health Association.

Park, P. (1992). **The discovery of particpatory research as a new scientific paradigm: Personal and intellectual accounts.** The American Sociologist, 23 (4), 29-42.

Park, P. (1993). **What is participatory research? A theoretical and methodological perspective.** In Park, Brydon-Miller, Hall & Jackson (Eds.) Voices of change. Toronto: Oise Press, 1-19.

Perrin, B. (1989, summer). **Literacy and health: Making the connection.** Health Promotion , 28 (1), 2-5.

Perrin, B. (1989). **Literacy and health project: Phase one. Making the world a healthier and safer place for people who can't read.** ERIC Document #ED346357.

Pincus, T. & Callahan, L.F. (1995). **What explains the association between socioeconomic status and health: Primarily access to medical care or mind-body variables?** Advance, 11 (1), 4-36.

Plimpton,S. & Root, J. (1994). **Materials and strategies that work in low literacy health communication.** Public Health Reports, 109(1), 36-42.

Prevalence of selected risk factors for chronic disease by education level in racial/ethnic populations-United States, 1991-1992. Morbidity and Mortality Weekly Report, 1994, 43 (48), 894-899.

Pugsley, R.S. (1990, March). **Vital statistics: Who is served by the Adult Education Program.** Washington, D.C.: U.S. Department of Education.

Reason, P. (1994). **Three approaches to participative inquiry.** In N.K. Denzin & Y.S. Lincoln (Eds), Handook of qualitative research. Newbury Park, CA: Sage.

Robertson, A. & Minkler, M. (1994). **New health promotion movement: A critical examination.** Health Education Quarterly, 21 (3), 296-311.

Robottom, I. & Colquhoun, D. (1992). **Participatory research, environmental health education and the politics of methods.** Health Education Research-Theory and Practice 7 (4), 457-469.

Rogers, C.R. (1969). **Freedom to learn.** Westerville, OH: Merrill.

Rowbotham, S. (1995). **What do women want? Women-centered values and the world as it is.** Feminist Review, 20, 40-69.

Rudd, R.E. (1995). **HEAL evaluation report.** Boston: Unpublished Report for World Education.

Rudd, R.E. & Comings, J.P. (1994). **Learner developed materials: An empowering product.** Health Education Quarterly, 21 (3), 313-327.

Ruzek, S. (1996). **Emerging models of women's health: Rethinking access, equity, and idealogical blindspots.** New York: Speech given at American Public Health Association Conference.

Sarri, R.C. & Sarri, C.M. (1990). **Organization and community change through participatory action research.** Paper presented at the International Schools of Social Work Biennial Conference, Lima, Peru, August, 1990.

Schmitz, C.C. (1995). **Lessons from the field: Implications of the community-based approach to improving health.** Presentation to the Annual Community Based Publish Health Meeting, June 1995.

Schneider, J.K., Hornberger, S., Booker, J., Davis, A. & Kralicek, R. (1993). **A medication discharge planning program: Measuring the effect on readmissions.** Clinical Nursing Research, 2 (1), pp.41-53.

Schoen, D.A. (1983). **The reflective practitioner: How professionals think in action.** New York: Basic Books.

Schoenholtz-Read, J. (1994). **The supervisor as gender analyst: Feminist perspectives on group supervision and training.** Los Angeles: Paper given at the American Psychological Association Convention.

Seahorn, J.J. (1992). **Cultures of inquiry· Mindmaps.** Santa Barbara, CA.: The Fielding Institute (Research session).

Simonson, L.J. & Bushaw, V.A. (1993, Spring). **Participatory action research: Easier said than done.** The American Sociologist.

Sissel, P.A. (1995). **Literacy and health: Are we overlooking the link?** Presentation at the Commission on Adult Basic Education Conference, June, 1995.

Sissel, P.A. & Hohn, M.D. (1996, Summer). **The future and potenial of community health and literacy education.** In Adult and Continuing Education No 70, 59-71.

Sissel, P.A. & Robbins, J.R. (1994). **Falling through the cracks: An ethnographic study of the Get Smart Delta Health Insurance Program.** Unpublished Report. Little Rock, AR: Center for Applied Research, University of Arkansas at Little Rock, Medical Science.

Slavin, R.E. (1997). **Educational psychology: Theory and practice** (5th ed.). Boston: Allyn-Bacon.

Smith, C. (1994). **Health education and adult literacy (HEAL) project final evaluation report.** Boston: World Education.

Student Action Health Team. (1996). **When learners become teachers.** The Change Agent. Boston: Issue 4, New England Literacy Resource Center.

Student Action Health Team. (1997). **Helping to break the circle of family violence.** Lawrence, MA.: Northeast SABES.

Surrey, J.L. (1987). **Relationship and empowerment.** Wellesley, MA: Stone Center for Developmental Services and Studies.

Szudy, E. & Arroyo, M.G. (1994). **The right to understand: Linking literacy to health and safety training.** Berkeley: University of California Press.

Tobi, M.A., Lippin, M. & Fingeret, H.A. (1991, December). **How adults with limited literacy cope with reading medication labels.** Durham, NC: Literacy South.

Tresserras, R., Canela, J., , Alvarez, J., Sentis, J. & Salleras, L. . (1992). **Infant mortality, per capita income and adult illiteracy: An ecological approach.** American Journal of Public Health , 82 (3), 435-438.

U.S. Bureau of the Census. (1993). **Statistical abstract of the United States: 1993.** Washington D..C: U.S. Government Printing Office.

U.S. Department of Education. (1992). **National Institute for Literacy fact sheet.** Washinton D.C.: U.S. Dept. of Education.

U.S. Department of Education, National Center for Education Statistics (1993). **Adult literacy in America: A first look at the results of the national adult literacy survey.** Washinton D.C.: U.S. Government Printing Office 0-356-371 QL3.

U.S. Department of Health & Human Services, Public Health Service. (1991). **Healthy people 2000: National Health Promotion and Disease Prevention Objectives.** Washington D.C.: U.S. Dept. of Health and Human Services, DHHS Publication No. (PHS) 91-50212.

U.S. Department of Health and Human Services (1994). **Morbidity and mortality weekly report** 43 (48), pp. 894-899.

Vella, J. (1994). **Learning to listen, learning to teach: The power of dialogue in educating adults.** San Francisco: Jossey Bass.

Wadsworth, Y. (Ed.). (1984). **Do it yourself action research.** St. Leonards, New South Wales, Australia: Allen & Unwin.

Wallace, P.E., Jr. (1994). **Post-hospital care for the underserved: A review.** Journal of Health Care for the Poor and Underserved 5 (4), 316-325.

Wallerstein, N. (1992). **Health and safety education for workers with low literacy or limited english skills.** American Journal of Industrial Medicine, 22, 751-765.

Wallerstein, N. & Bernstein, E. (1988). **Empowerment education: Freire's ideas adapted to health education.** Health Education Quarterly, 15 (4), 379-394.

Wallerstein, N. & Weinger, M. (1992). **Health and safety educatin for worker empowerment.** In American Journal of Industrial Medicine, 22, 619-635.

Weiss, B.D., Blanchard, J.S., McGee, D.L., Hart, G., Warren, B., Burgoon, M. & Smith, K.J. (1994). **Illiteracy among medicaid recipients and its relationship to health care costs.** Journal of Health Care for the Poor and Underserved, 5 (2), 99-111.

Weiss, B.D., Hart, G., McGee, D. & D'Estelle, S. (1992). **Health status of illiterate adults: Status among persons with low literacy skills.** Journal of American Board of Family Practice, 5(3), 257-264.

Weiss, B.D., Hart, G., & Pust, R. (1992). **The relationship between literacy and health.** Journal of Health Care for the Poor and Underserved, 1(4), 351-363.

Whyte, W.F. (1991). **Participatory action research.** Newbury Park, CA: Sage Publications.

Williams, M.V., Parker, R., Baker, D., Parikh, N., Pitkin, K. Coates, W., & Nurss, J. (1995). **Inadequate functional health literacy among patients at two public hospitals.** Journal of the American Medical Association, 274 (21), 1677-1682.

Whiton, L. (1995). **Ask the learner: How does health education impact the lives of adult education learners?** Unpublished Evaluation Report, June 1995. Boston: Comprehensive Health Education Project, MA Department of Education.

Yin, R.K. (1994). **Case study research: Design and methods (2nd ed.).** Thousand Oaks, CA.: Sage Publications.

Zambrana, R.E. & Ellis, B.K. (1995). **Contemporary research issues in Hispanic/Latino women's health.** In D.L. Adams (Ed.) Health issues for women of color. Thousand Oaks, CA: Sage.

Zimmerman, M. (1994). **Empowerment forum: A dialogue between guest editorial board members.** Health Education Quarterly 21 (3), 281-294.

Appendix A

Student Evaluation Survey in the Breast, Cervical, and Testicular Cancer Education Program

Developed by the Student Action Health Team

Section I - Your Opinion on Learning About Breast, Cervical and Testicular Cancer

Please respond to the following statements using an agree-disagree scale of 1-5. "1" means you strongly agree with the statement. "5" means you strongly disagree with the statement. You may mark your response anywhere from 1 to 5.
Actual scale is not shown here.

1. Learning about breast, cervical and testicular cancer was important to me.

2. The information about breast, cervical and testicular cancer was new to me.

3. I understand much more about breast, cervical and testicular cancer that I did before.

4. **(for ESOL students only).** Translating the information into my native language was helpful to me.

5. Operation Bootstrap is a good place for me to learn about health issues like breast, cervical, and testicular cancer.

6. Learning about health issues from other students like me is a good way to learn about health.

Section II - Your Opinion About The Effectiveness of the Educational Activities

Please respond to the following statement about the educational activities using a scale of 1 to 5. "1" means you found the educational activity very helpful. "5" means the activity was not very helpful to you. You may mark you response anywhere from 1 to 5. **Actual scale is not shown here.**

1. True and False

2. Agree/Disagree

3. Breast and Testicular Self-Exams

4. Brochures about Breast, Cervical and Testicular Cancer

5. Dramas on "Going to the Doctor"

6. Written Information about Where to Go for Free or Reduced Fee Care

Section III - What Action Have You Taken?

Please circle you answer.

1. **(for men)** I am doing testicular self-exams. Yes No

2. **(for women)** I am doing breast self-exams. Yes No

3. **(for women)** I have gone for a Pap test. Yes No

4. **(for women)** I have gone for a mammogram Yes No

If you have gone for a mammogram, please tell how old you are.
I am_____________ years old.

5. I have shared what I learned about breast, cervical, and testicular cancer with family and friends Yes No

If you have shared the information, please tell us who you share the information with. Circle the people with whom you shared the information.

Wife Husband Children Sisster Brother Aunt Uncle Grandmother

Grandfather Friends Other

Additional Comments ____

____

Created by Marcia Drew Hohn, NIFL Literacy Leader Fellowship Project, 1996-1997

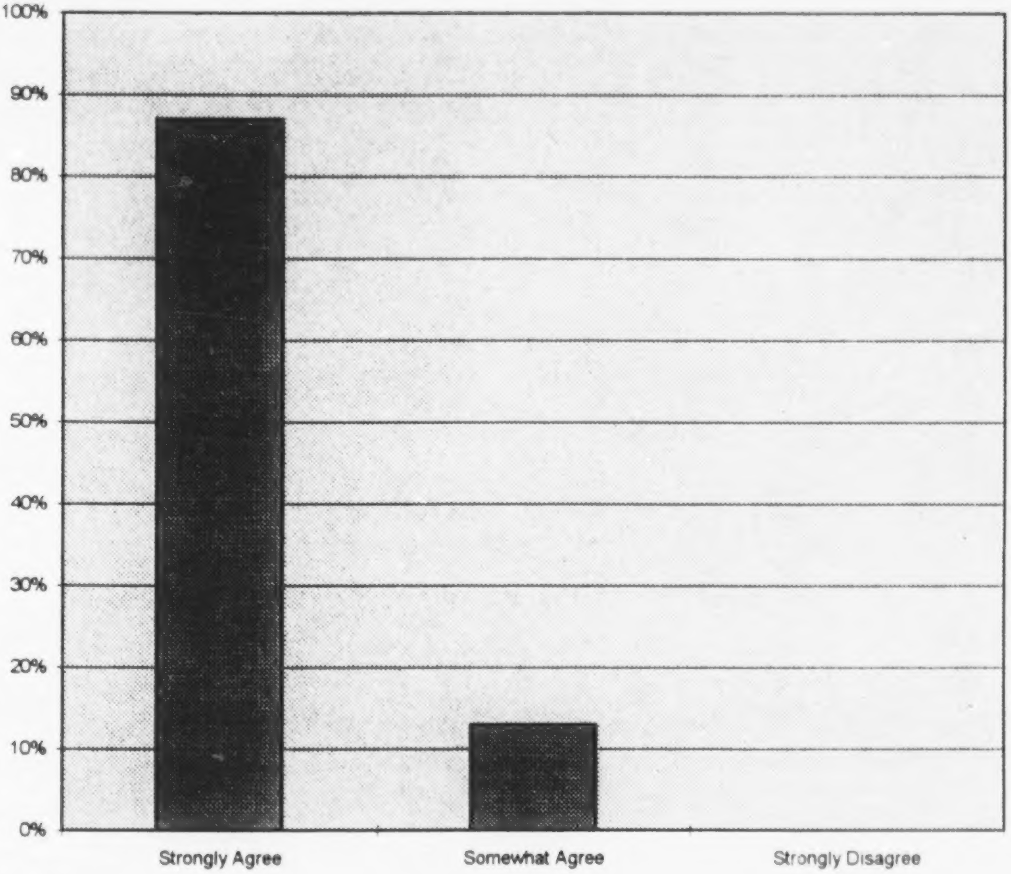
Appendix B

Student Evaluation Survey Results in the Breast, Cervical and Testicular Cancer Education Program

Complied, Analyzed and Graphed by the Student Action Health Team

Section One

1. Learning about breast, cervical and testicular cancer was important to me.

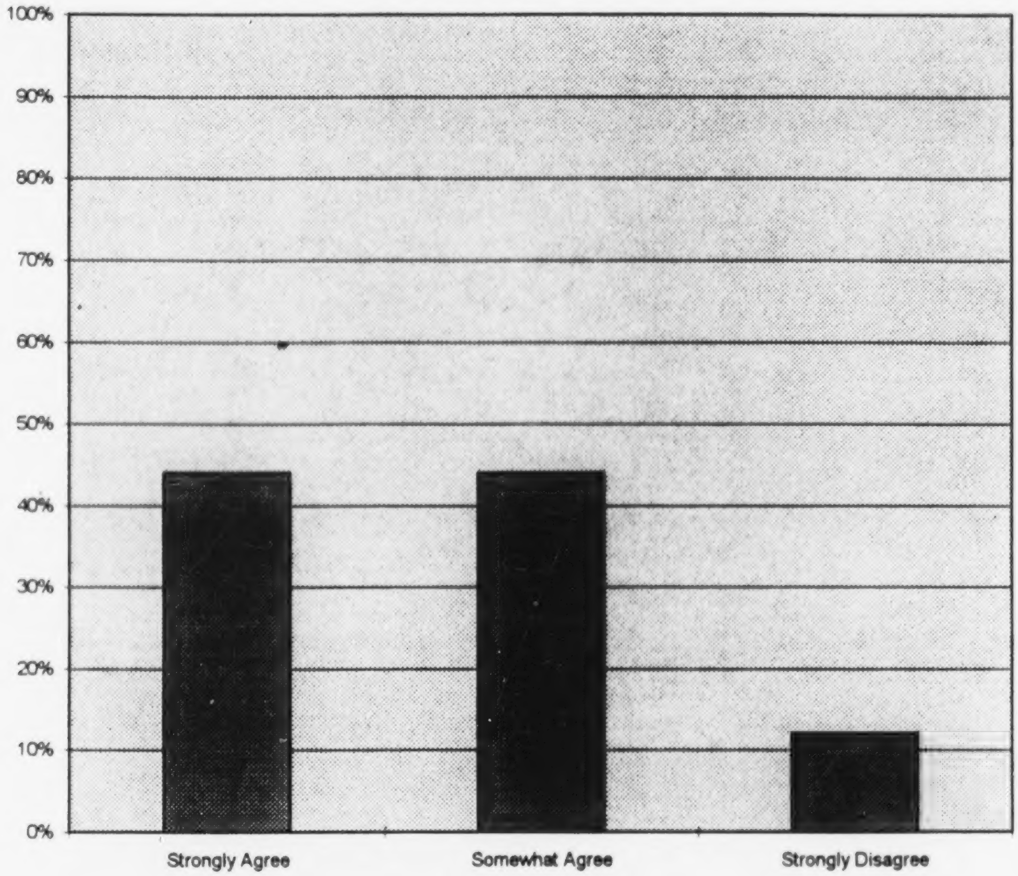


BEST COPY AVAILABLE

Responses by Literacy Students at Operation Bootstrap about value of Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section One

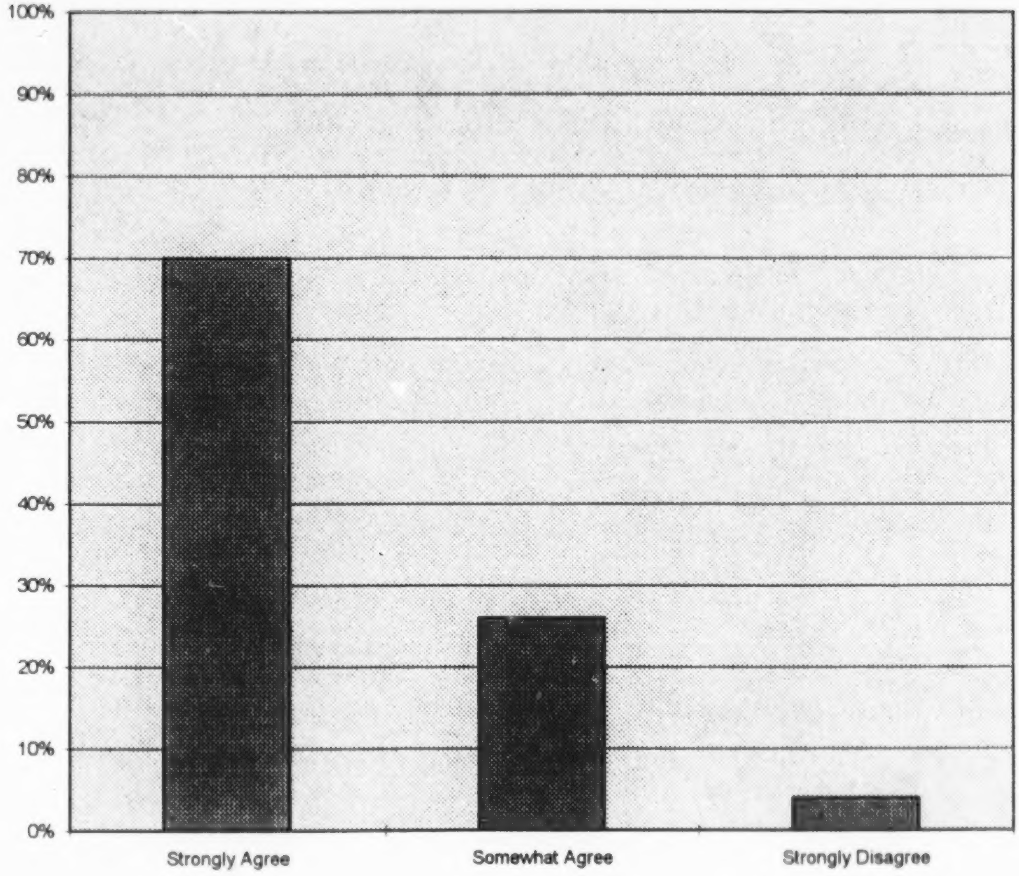
2. The information about breast, cervical and testicular cancer was new to me.



Responses by Literacy Students at Operation Bootstrap about value of Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section One

3. I understand much more about breast, cervical and testicular cancer than I did before.

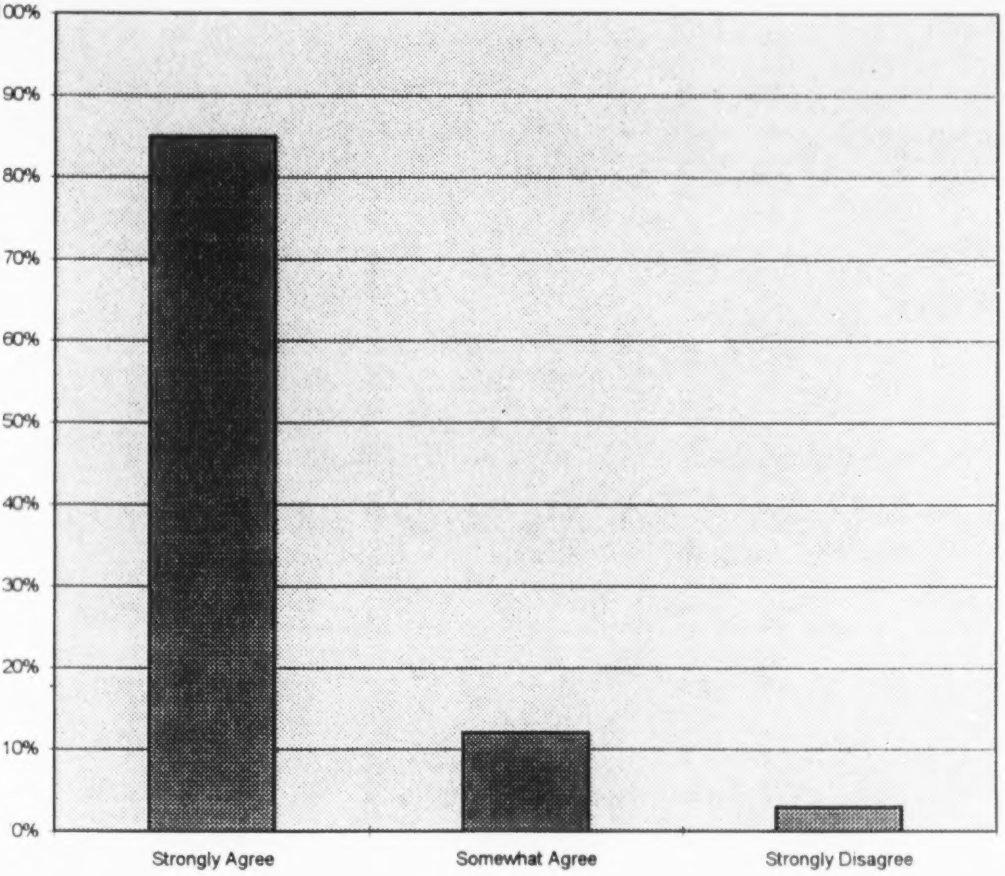


BEST COPY AVAILABLE

Responses by Literacy Students at Operation Bootstrap about value of Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section One

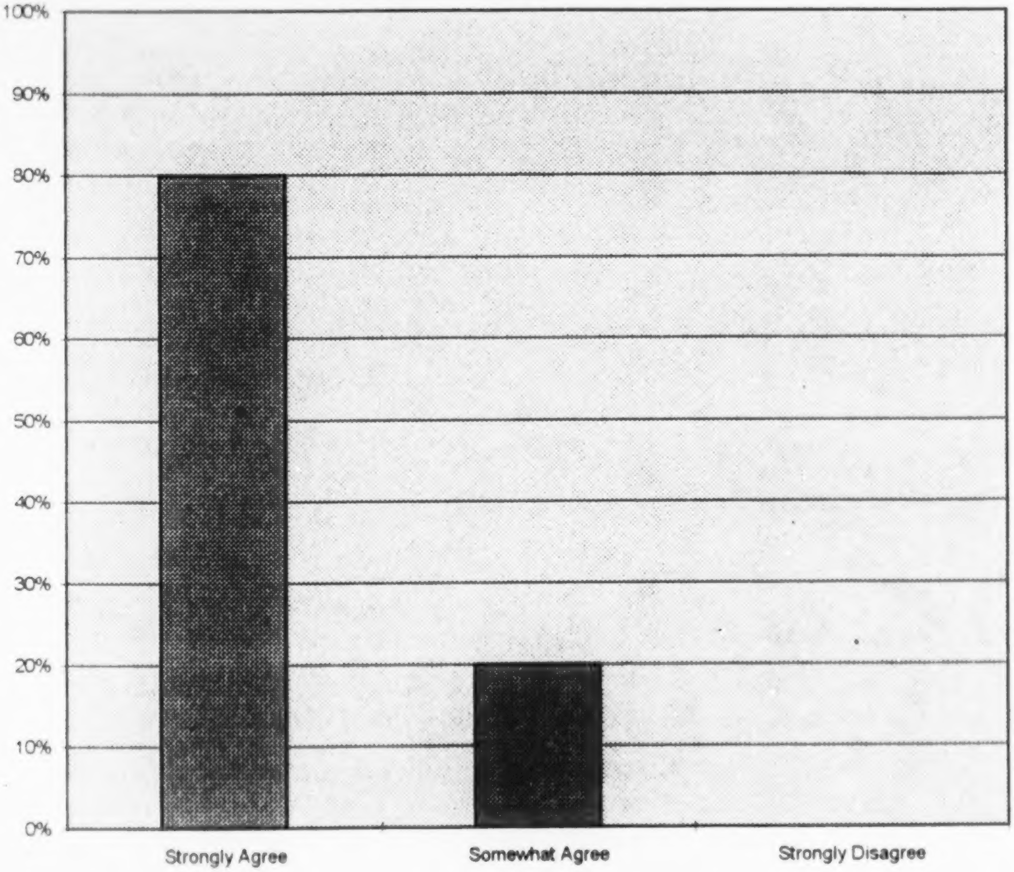
4. Translating the information into my native language was helpful to me. (For ESL students only.)



Responses by Literacy Students at Operation Bootstrap about value of Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section One

5. Operation Bootstrap is a good place for me to learn about health issues like breast, cervical and testicular cancer.

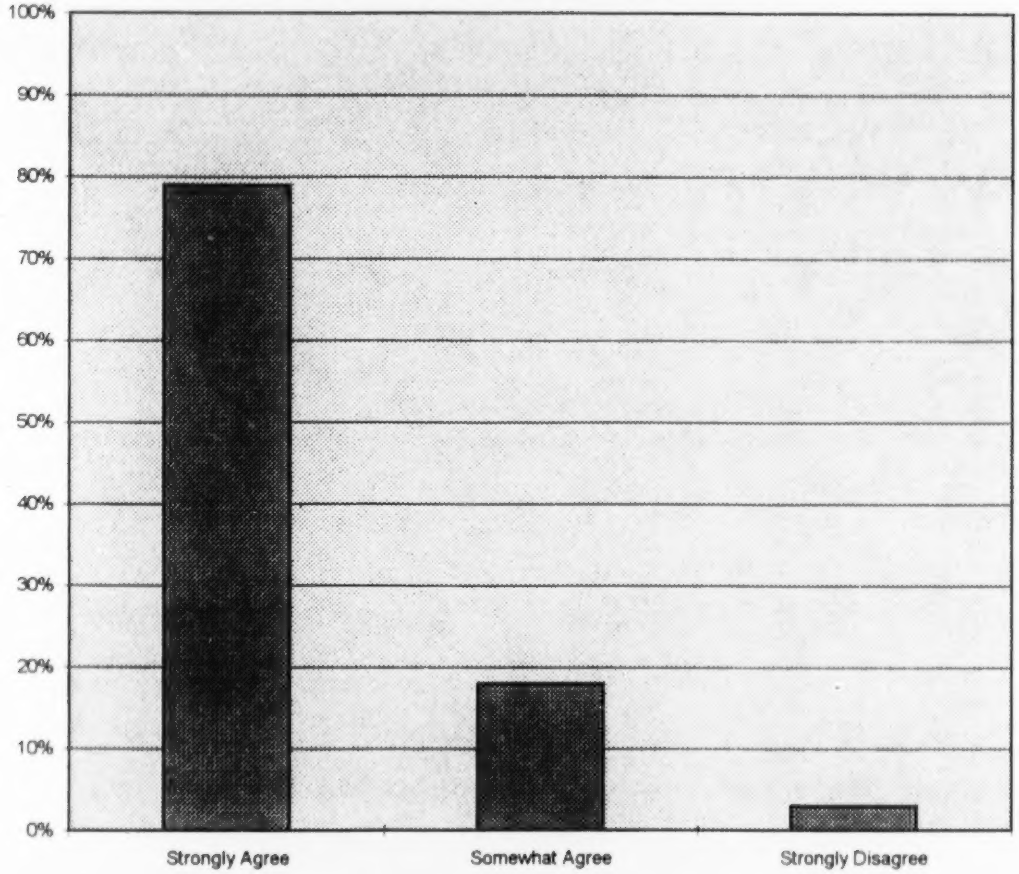


BEST COPY AVAILABLE

Responses by Literacy Students at Operation Bootstrap about value of Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section One

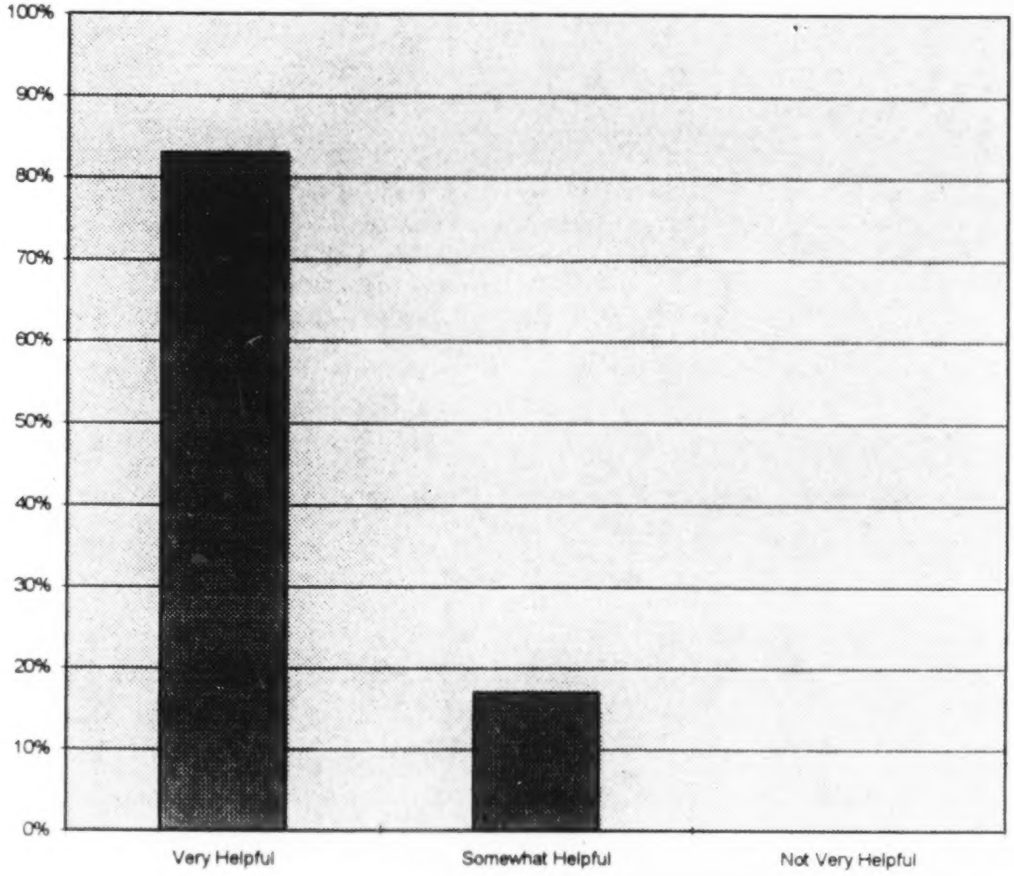
6. Learning about health issues from other students like me is a good way to learn about health.



Responses by Literacy Students at Operation Bootstrap about value of Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section Two

1. True or False Activities.

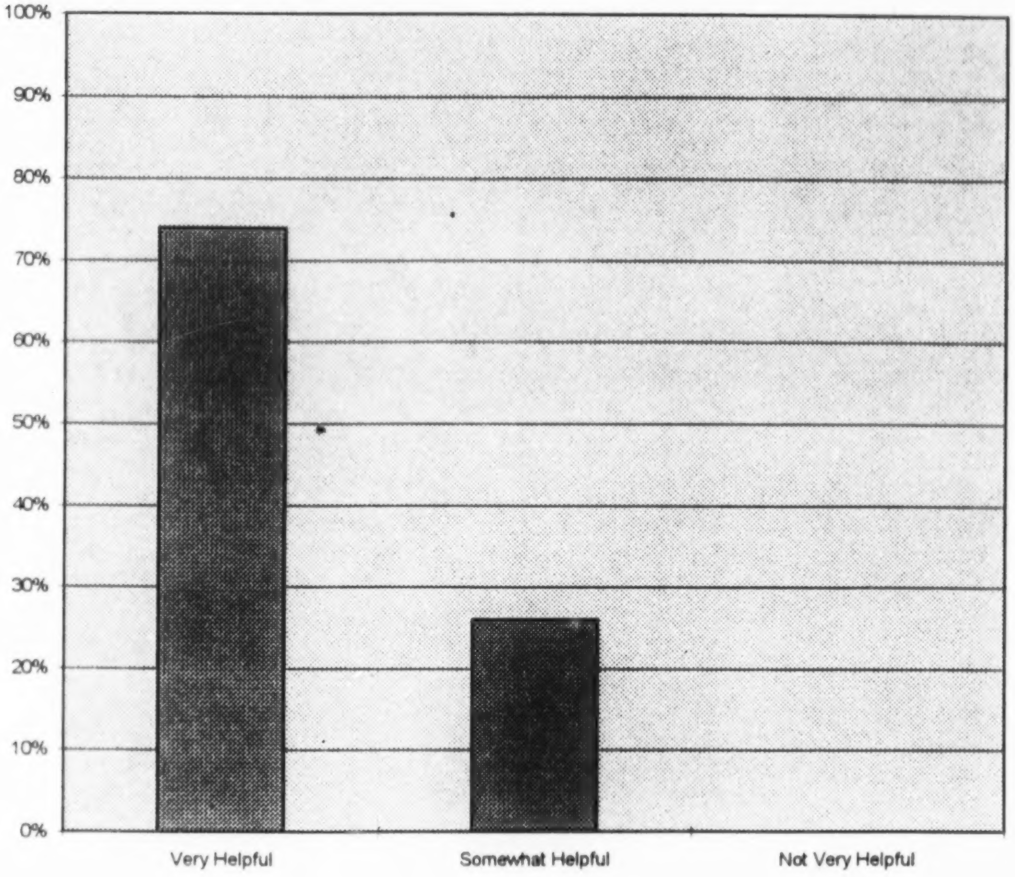


BEST COPY AVAILABLE

Opinions of Literacy Students at Operation Bootstrap about effectiveness of the Educational Activities on Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section Two

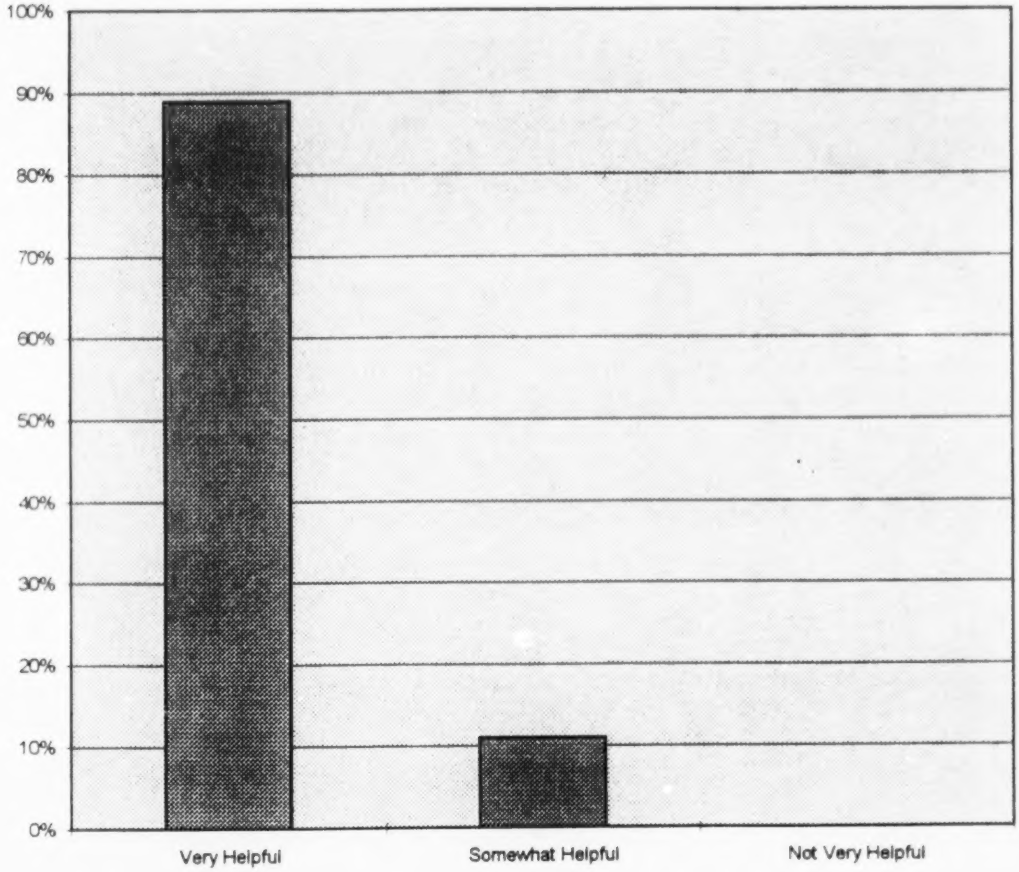
2. Agree/Disagree Activities.



Opinions of Literacy Students at Operation Bootstrap about effectiveness of the Educational Activities on Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section Two

3. Breast Self Exams and Testicular Self Exams.

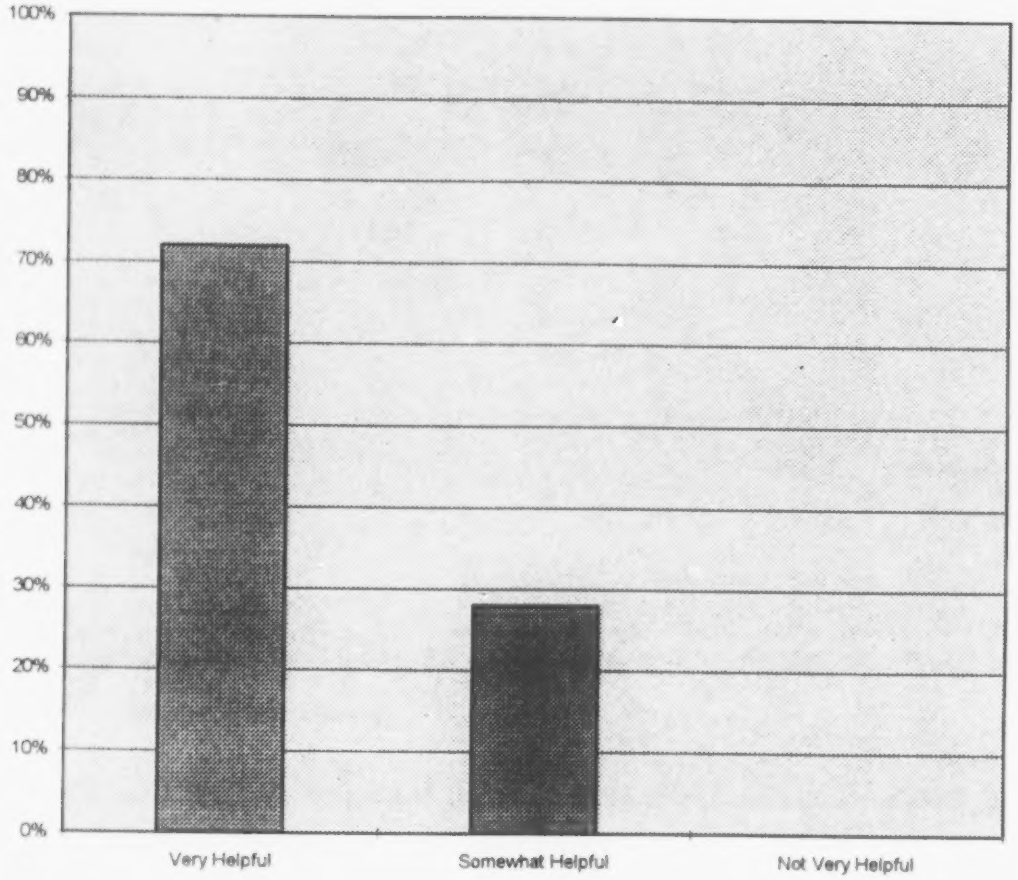


BEST COPY AVAILABLE

Opinions of Literacy Students at Operation Bootstrap about effectiveness of the Educational Activities on Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section Two

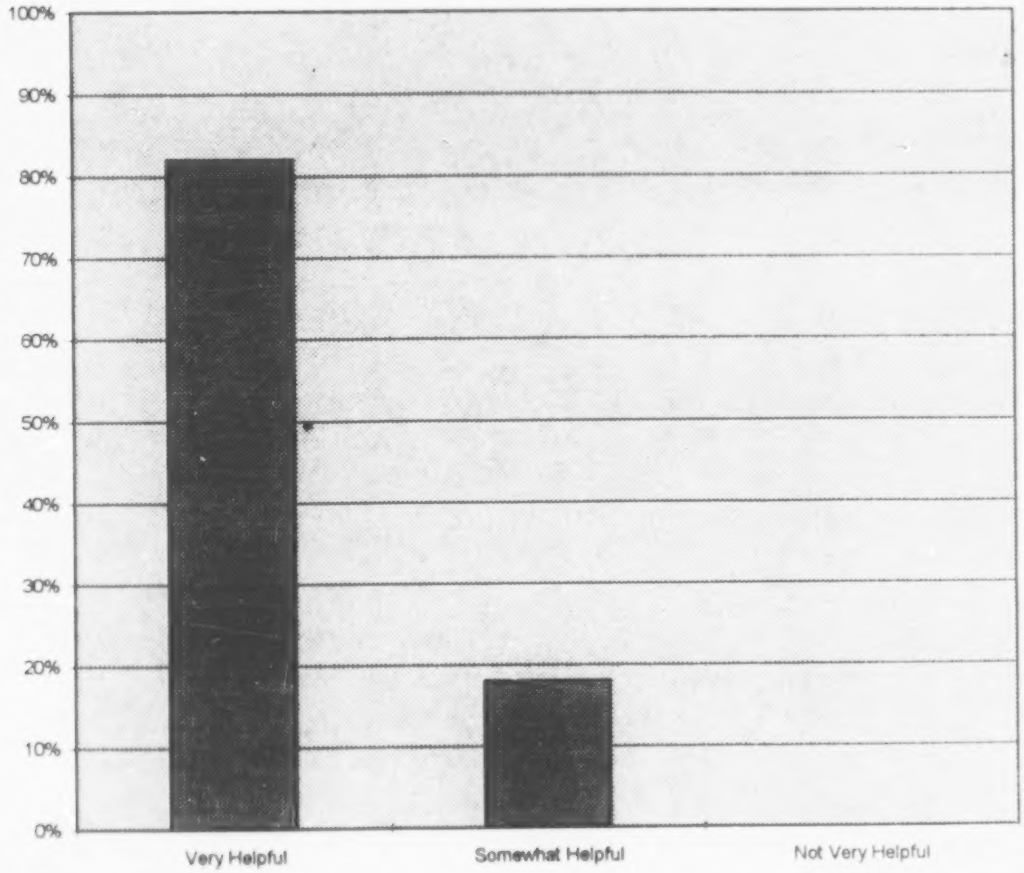
4. Brochures about breast, cervical and testicular cancer.



Opinions of Literacy Students at Operation Bootstrap about effectiveness of the Educational Activities on Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section Two

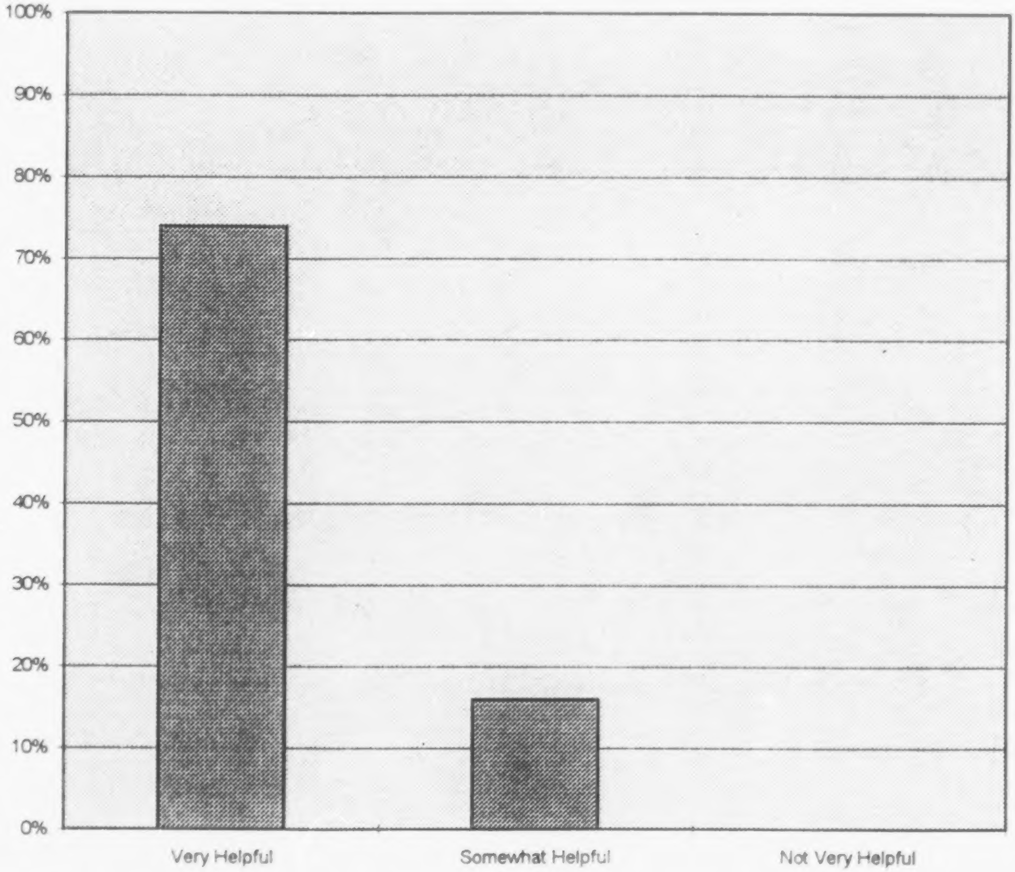
5. Drama on "Going To The Doctor".



Opinions of Literacy Students at Operation Bootstrap about effectiveness of the Educational Activities on Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section Two

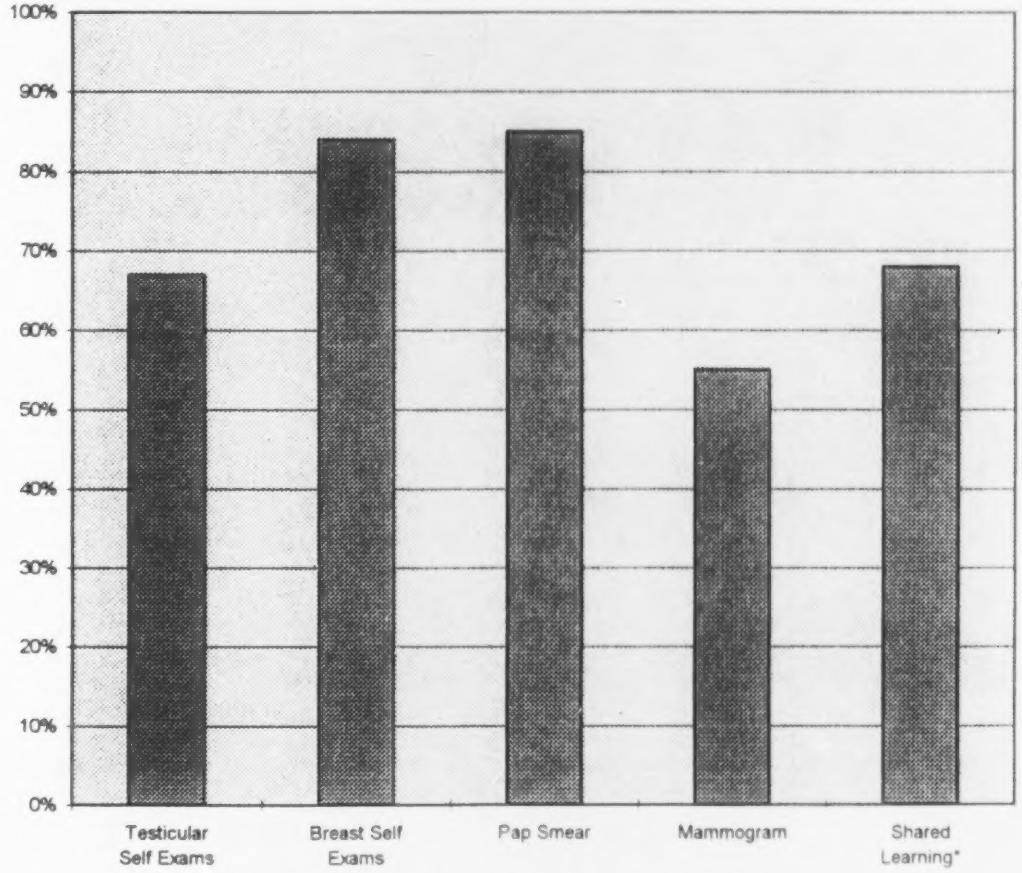
6. Written information about "Where To Go For Free Or Reduced Fee Care".



Opinions of Literacy Students at Operation Bootstrap about effectiveness of the Educational Activities on Breast, Cervical and Testicular Cancer Education at their program - April 1996.

Section Three

Action taken by Literacy Students at Operation Bootstrap two months after the Breast, Cervical and Testicular Cancer Education Program by the Student Action Health Team.



Data collected from sample of students in six participating classrooms (N=42) with the following distribution of characteristics -- Low Income (98%), Female (73%), Male (27%), Hispanic (40%), White (32%), Black (20%), Asian (7%), American Indian (1%).

***Shared what I learned with family and friends.**

Appendix C

Evaluation Interview Questions in the Family Violence Education Program Developed by the Student Action Health Team

After Session II: Children Witnessing Violence in the Home

1. What do you think you learned about children witnessing violence at home?

2. Was this information that the team presented to you new? What new information was the most important to you?

3. Did you like how the team presented the information to you, using drama, etc.?

4. What were your favorite activities and why?

5. Do you think that the Broad Street Learning Center is a good place to learn about health? Do you see this health education as taking away from your overall learning or adding to it? If adding, in what ways does it add?

After Session III: Man-to-Woman Violence

1. Can you tell me what you learned from the session about man-woman violence?

2. What parts were most helpful to you?

3. Did you share this information? Who did you share it with?

4. Did you take any action as a result of what you learned?

5. Do you think this information added to your education? If so, in what ways?

National Institute for Literacy
800 Connecticut Ave. NW
Suite 200
Washington, DC 20006

*To order more copies of
this publication, call:*
1-800-228-8813